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ABSTRACT

Presented are conference reports including an opening address on the economic benefits of programs for the mentally retarded (MR), and eight papers discussing the problem of mental retardation in the Caribbean. Two papers on preschool age children, respectively, consider the identification and assessment of MR children in the Caribbean and present a study of West Indian children which explored the relation between preschool environment and mental retardation. Teacher training at the University of Puerto Rico and alternatives to public institutional care are discussed in two articles about school age children. Outmoded ideas as impediments to the employment of MR adults are described along with sheltered facilities and occupations for the mentally handicapped. Also presented are a pilot study of the families of MR children in Trinidad and a discussion of the adjustment of the community to the mentally retarded. Discussions that followed the presentation of each paper are included. Proposals for establishing a coordinating center for services to the MR in the Caribbean and for making recommendations to the Caribbean governments are noted. (GW)

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MENTAL RETARDATION IN THE CARIBBEAN

NEEDS RESOURCES AND APPROACHES

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Proceedings of
The First Caribbean Mental Retardation Conference

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Mental Retardation In The Caribbean

Needs, Resources, Approaches

The Proceedings of the First Caribbean
Mental Retardation Conference
held at
The University of the West Indies,
Mona, Jamaica

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The President's Committee on Mental Retardation

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FOREWORD

The First Caribbean Mental Retardation Conference arose out of the independent inspirations of Miss Frances McGrath and Dr. Matthew Beaubrun that there was a need for the Caribbean countries to meet and exchange ideas on the subject of mental retardation.

These ideas were crystallised and enthusiastically discussed at a visit to Jamaica of Dr. Patrick Doyle and Mr. Edward L. Johnstone of the President's Committee on Mental Retardation.

It was recognised that many of the islands have no facilities for the mentally retarded, that resources are limited and specialised personnel almost completely lacking. It was therefore necessary for the subject matter to be broad in order to cover a lot of ground. For this reason, some of the problems were perhaps considered rather superficially. It is also possible that some of the delegates did not get what they were seeking, which in some cases was a blue-print for the establishment of facilities. It was also recognised that what operates successfully in a developed country is not necessarily ideal in an undeveloped country and in many instances it is unrealistic to translate a situation directly from North America to the Caribbean.

However many points of great value emerged. There was obviously a need for such a meeting as all delegates reacted with enthusiasm to the topics discussed. Particular emphasis was placed on the need for developing services and facilities which could be operated or delivered by local people without high qualifications.

The outstanding needs are of course in personnel with knowledge and experience in this field, however plans and suggestions were made which would attempt to bridge the gap, by having short training courses for people already working on the fringes of the field.

Certainly the exchanges made at the conference inspired many of the delegates who came from less developed areas to go back and start something, however it was recognised that unless there was continuing support and encouragement from a central body these efforts could just fizzle out and not make any lasting impression. Therefore the most important suggestion was the universally felt need for a co-ordinating body or Secretariat in the Caribbean which could gather and disseminate information and advice for the member countries. Such a Secretariat would be the "technical arm" of a Caribbean Association and would develop projects and obtain expertise from appropriate sources in the United States, Canada and Europe. This aspect is described in more detail in the report of the final session of the conference and the immediate post-conference meetings.

The report of the proceedings follows the format of the conference itself which was age group structured. Each main session consisted of a plenary session of two topics. The participants then split into two groups to discuss simultaneously the two topics. Attempts were made to get views and facts from all the contributing countries. These efforts were slightly hampered by language problems as it was not possible to have simultaneous translations.

During the first session the problems of diagnosis and assessment of mental retardation and the effect of the social environment on the development of mild retardation in the Commonwealth Caribbean were discussed. It was apparent that there were several prime needs; the need for paramedical personnel to detect and assess retardation, the need for tests standardised for the culture, and the need for more intensive study of the effect of the environment. Early detection of children exposed to retarding environment influences should lead to the institution of a programme designed to improve the situation.

The session on teacher training recognised the needs of early production of trained teachers and implementation of special education courses in already established teacher training institutions. The existing lack of institutional facilities should be continued but with support being given to families by development of schools, day nurseries, hostels and family type groupings.

The session on open and sheltered employment opened our eyes to the wide possibilities existing in the Caribbean for the retarded. However it was well taken that any attempts at open employment would require excellent public relations and education and training of the retarded themselves to be good workers. Public education and relations were stressed further in the sessions on family and community adjustment. In fact one gained the impression that by good public relations one might accomplish almost everything and the rest would follow! Perhaps this is a slightly exaggerated view, and if one wishes to impress the public with how normal the retarded are, one has to have facilities for demonstrating this.

In the final session the need for continuing collaboration and the date and time of a second conference were established.

These proceedings were edited from prepared papers and the transcribed tapes of all the sessions. The editor wishes to express particular appreciation to Mr. Noel Ritch of Stanley Motta Limited for the excellent recording, Mrs. Cynthia Royal for the transcribing and Mrs. Marion Briscoe for the unfailing high quality of her secretarial assistance throughout the planning of the conference and production of the proceedings. Without Professor Delia Lugo much of the Spanish interchange would have been missed. One could not fail to mention her delivering her own paper first in English then in Spanish, translating Mr. Johnstone's into Spanish and finally translating during the discussion group! The conference was also indebted to Mrs. Nesta Patrick for her work in travelling the Eastern Caribbean to stimulate participation in the conference.

As an outcome of the conference three projects are in preparation or operation; standardisation of the Bayley Scales of Infant Development, a teacher training summer school for 1971 in Jamaica, and a seminar on programme planning and development. The Co-ordinating Committee will meet in April, 1971 to discuss the further progress of a Secretariat and a Caribbean Association.

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OPENING ADDRESS

"The Economic Benefits of Programmes for the Retarded'

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Department of Health Education & Welfare,
Washington, D.C.

September 7, 1970

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OPENING ADDRESS

It is a pleasure to have the opportunity to present some ideas regarding mental retardation programs to this distinguished group. It is also a bit presumptive to address one's self to economic factors when we should probably be concerned with the humanitarian, personal, family and social aspects of service to the disadvantaged. But in these days of stock-taking and competing priorities, frequently the question we are asked is: "I have no quarrel with the humanism of what you propose, but what will it cost and how can I afford it?" I would be so bold as to suggest as the take-off point for this presentation that the question we should address ourselves to is not whether we can afford it, but whether we can afford **not** to do it.

I should also apologize at the outset for the parochial nature of my paper. It is based on U.S. experience only – but that is a factor of my own knowledge and experience in a program designed to restore physically and mentally disabled individuals to some type of remunerative occupation as well as the nature of the available data on this subject.

One difficulty in speaking of the economic benefits of programs for the retarded is that most of the meagre data we have is for broad groups, not specifically for the mentally retarded. Still, even this may be instructive, on the assumption (for which we have some evidence) that mentally retarded clients are roughly in the middle of the pack, or perhaps above average, in returning benefits.

Let me give you some idea of what services (not all of them good) to the retarded cost in the United States: –

In its 1967 report, the President's Committee on Mental Retardation described mental retardation residental facilities as "a disgrace to the Nation." They are plagued by overcrowding, understaffing, and under-financing. Many are located in rural, out-of-the-way places, and most of them are "hand-me-down" buildings fifty or more years old. The per diem cost per person in 1967 in public institutions for the mentally retarded was only $7.60, compared to $7.00 for large animals in our five largest zoos.

Most mental retardation institutions are from 25% to 50% above rated bed capacity, and this, plus under-staffing and poor financing. lead to unbelievable abuses as documented in "Purgatory" by Burton Blatt[1]. These include bars on windows, locks on doors, incredible overcrowding, poor sanitation, solitary confinement for disobeying rules, use of physical restraints, poor food, lack of medical care, and no recreation.

In 1962, the President's Panel on Mental Retardation estimated that 50,000 new bed spaces were needed for the mentally retarded, and would cost $40,000 per bed in construction costs. Compare this $2 billion cost with what might be done via other programs, such as habilitation and foster care.

Even though fewer than 5% of the mentally retarded in the United States reside in institutions, more money is spent to maintain them than is spent for any of the public programs which serve the remaining 95%.

In 1968, $1.2 billion was spent for all institution residental care for mentally retarded clients and that is between $4,000 to $5,000 per resident per year.

All types of Special Education programs for mental retardation cost a bit over $1 billion per year, and serve perhaps 625,000 mentally retarded students at any point in time. This equals $1,600 per student per year.

Regular public school classes serve perhaps an additional 670,000 mentally retarded students at an annual cost of $550 million ($820 per year each).

Two hundred and thirty-five mental retardation clinics serve 66,000 clients per year at a cost of $13 million; and outpatient psychiatric clinics serve 47,000 mentally retarded clients per year at a cost of $11 million.

State and Federal vocational rehabilitation service programs spend $51 million on them per year.

Sheltered workshops are serving only about 26,000 mentally retarded clients at any one time, at an annual cost of $26 million.

Transfer payments (Federal income maintenance, in effect) amount to $240 million per year for mentally retarded persons – $115 million in public assistance (as aid to permanently and totally disabled), and $125 million from Trust Funds (Social Security benefits for disabled minors, etc.).

This is a lot of money! And what we get for it is not clear. But let us address ourselves to some data which do tell us what is happening.

In 1965, Dr. Ronald W. Conley[2] "divided annual program costs" into "the estimated present value of future outputs due to each year's rehabilitations" and concluded that "each dollar expended by rehabilitation agencies set in motion or maintained a stream of future outputs worth at least $10 and perhaps as much as $17." However, he did not give separate figures for the mentally retarded.

In 1967, Lawrence Mars[3] found that clients rehabilitated during fiscal year 1966 "will experience an increase of $35 in earnings and value of work activity over their working lives for every dollar expended on them." Again, no separate figure for the mentally retarded was given.

A project in Wood Country, Wisconsin, was designed to establish that the vocational rehabilitation process can be successfully and profitably extended not only to more of the physically handicapped **but also to the culturally disadvantaged**. It did a benefit-cost analysis of the outcomes of services rendered to project clients, based on followup six months after closure. Using the same model as Mars the researchers compared benefits ("increased lifetime earnings attributable to vocational rehabilitation") with the cost of services, and derived benefit ratios for various groups of clients in the experimental Wood County. These ranged from 22 to 1 for the mentally ill up to

69 to 1 for the culturally disadvantaged. For all mentally retarded clients the ratio was 30 to 1 (28 to 1 for mentally retarded wage earners and 44 to 1 for mentally retarded homemakers). We should note that non-quantifiable social and psychological benefits were not included in this analysis.

Incidentally, one of the most striking findings of this study was the high benefit ratio for the disadvantaged: 69 to 1. Two hundred and twenty-five of these clients had a projected **increase** in lifetime earnings of over $10 million from rehabilitation services costing less than $150,000.

Another striking facet of this study: 92 of these disadvantaged clients were on welfare when referred, but at followup, annual welfare payments to them had been reduced by $30,239, while at the same time their earnings had increased by $251,686 per year, giving a net yearly financial gain for the 92 of $281,925, or about $3,000 per client (compared to an average cost per rehabilitant for all culturally handicapped of $515).

More recently (1969), Ronald Conley4 used a more conservative approach, recognizing in some detail that **program costs** incurred by Federal and State agencies substantially **understate** the total social costs of rehabilitation services.

To estimate the true social cost of rehabilitation he increased program costs by 42% plus 35% of estimated annual earnings at closure.

Using what he called "a generous estimate of social cost compared with a conservative estimate of social gain," he came out with a range of benefit-cost ratio. The range for fiscal year 1967 rehabilitants was from 3.8 to 1 to 24 to 1 (program costs **not** adjusted, future earnings **undiscounted**, and earnings rate **for week prior to acceptance** used as basis for comparison).

Conley also estimated that yearly **increase** in Federal income taxes due to rehabilitation tripled from 1961 to 1967, while the yearly **saving** in public assistance payments almost doubled, giving a net benefit from rehabilitation ranging from $19 million in 1961 to $45.4 million in 1967.

Related to this, he estimated that it takes in the range of only 3.5 years (1961) to 5.1 years (1967) for taxpayers to recoup their share of rehabilitation costs out of increased Federal taxes paid by rehabilitants and lowered welfare payments made to them. He concludes, "Clearly, even to non-rehabilitants, rehabilitation is a profitable undertaking, since the average number of years in which most rehabilitants will work is three to four times the number of years needed to repay taxpayers."

His overall summary of benefits from fiscal year 1967 rehabilitants:

"More than 170,000 disabled persons were rehabilitated through the State-Federal vocational rehabilitation program in fiscal year 1967. A conservative estimate of their increased lifetime earnings is about $4.7 billion, about $8 for each dollar of the social cost of rehabilitation services. If we discount these future increased earnings at 4 percent, the latter figure falls to a little less than $5. Taxpayers share substantially in these earnings, as the increased taxes paid by the rehabilitants and the reduction in tax-supported payments for their maintenance amount to perhaps as much as 25% of the total increase in earnings. Since rehabilitants with the highest earnings at closure also tend to be those with the highest earnings at acceptance and are the most expensive to rehabilitate, we are led to the surprising conclusion that from the standpoint of economic efficiency, it may be as desirable to rehabilitate the less productive disabled as the more productive."

How do mental retardation clients stack up in relation to all this? Conley gives no separate figures but does note that training costs for mental retardation clients were less than a quarter the average for all rehabilitants, and we know they are younger than the average client at closure, so may have more years to work. The benefits from rehabilitation for the mentally retarded should also be considered in relation to Conley's "surprising conclusion" just above. that "from the standpoint of economic efficiency, it may be as desirable to rehabilitate the less productive disabled as the more productive."

Our Division of Statistics and Studies did a study (Statistical Notes, No. 14, June 1969) of earnings-cost ratios for selected groups of fiscal year 1967 clients. This study included only direct case services costs, which as we know are only part of total programme costs, just as the latter are only part of true social costs. The increase in annual rate of earnings from acceptance to closure was divided by direct case services costs.

The real importance from this study lies in the ratios found for different groups of clients. They ranged from 2.2 to 1 for the blind to 10.39 to 1 for alcoholics. For mental retardation clients, the ratio was 4.65 to 1, which is above the average for all clients.

Thus, we have some evidence here and from the "Profile of mentally retarded clients. . . . .," the Wood County Project, the Conley's "surprising conclusion", that benefit ratios for the mentally retarded are at least as high as the average for all rehabilitants, and probably higher.

At a more elemental level, training in self-bathing, dressing, and feeding give the biggest savings, according to one study, which estimated that for these three categories of care savings were $13,120 per year for the forty mentally retarded residents studied.

This estimate may be minimal, for the indirect benefits of good self-care are also great. This is obvious in the vocational area and the payoff in better health and less illness is no doubt also significant. A recent news item, for example, told of an epidemic of hepatitis affecting over two hundred institutionalized mentally retarded young persons, which may well have been caused or at least spread by poor sanitation and self-care.

Let me give you a contrast. In 1967, $600 million a year was being spent for 200,000 mentally retarded children and adults in institutions. Many of these, who would be capable of self-support in communities, were being exploited by too many institutions by being forced to work too many hours without pay.

Compare this with the fact that in 1968 $500 million was being spent for foster care for 656,000 children – less than one-third as much per person. It is ironic that the high-cost, low-love setting of an institution is being utilized so much for mentally retarded persons who might be better off in a medium-love, low-cost foster home!

Further, $30,000 per year will support a small adoption service specializing in placement of mentally retarded children, versus perhaps $100,000 per mentally retarded person for lifetime institutionalization.

The long-term cost for keeping one mentally retarded person institutionalized may run as high as $100,000 and range from $2,000 to $10,000 per year. By contrast, many can be given vocational training at a cost of no more than $1,000 to $9,000 – **about one year's maintenance cost in an institution** – that

will enable them to earn over $3,000 per year, some of which will be returned to the community in taxes. Thus, the net gain from habilitation versus institutionalization is very great per person, especially over the longer term.

We have in the U.S. a Federal employment programme for the mentally retarded. This programme, a co-operative one between the Civil Service Commission and the State vocational rehabilitation agencies, has progressed from temporary to permanent status and is now integrated with the Federal programme to employ the handicapped.

It began on February 5, 1963, with President Kennedy's special message to Congress recommending a broad national programme to combat mental retardation, and with Eunice Shriver's "fiery speech" on May 9, at the annual meeting of the President's Committee on Employment of the Handicapped, in which she chided the government for failing to hire the mentally retarded.

Since then, a long series of some forty-five actions (mostly official) have occurred, culminating on July 30, 1965, in the issuance to the Civil Service regions of a joint memo from the Department of Health, Education, and Welfare and the Civil Service Commission entitled "Experimental Effort in Federal Employment of the Mentally Retarded in Selected Metropolitan Areas".

The first placement occurred on January 8, 1964, and by December 31, 1968, forty-two Federal departments and agencies had executed written agreements with the Civil Service Commission to use the Schedule A authority under section 213,3102 (t) to employ mentally retarded persons, and by the latter date 5,784 placements (1,276 in the District of Columbia area, 4,508 in the field) had been made. All fifty State vocational rehabilitation agencies had made referrals and sixty-six jobs titles were involved. It is estimated that as of now about 7,000 have been placed. Overall, about three-fourths have been rated "satisfactory" or "very good" by their supervisors.

The written agreement requires a statement of agency support; list of positions, titles, and grades to be assigned the mentally retarded; and a statement that prior to hiring a mentally retarded person it will obtain a certificate from the appropriate State vocational rehabilitation agency that the retarded person can perform the duties of the position, is physically qualified to do so without hazard to self or others, and is socially competent to maintain himself while so doing. The Federal agency is also committed to fully utilize the advice and assistance of the State vocational rehabilitation agency regarding supervision, training, and post-placement counseling of the employee, and agrees not to terminate him without prior notice to the vocational rehabilitation counselor concerned.

Only 9% of these retardates have been separated for inability to perform or make social adjustments, and their cumulative separation rate from February 1964 through December 1967 was only 28.8%, small in comparison with the normal turnover rate in such job classifications. Assuming that 5,000 of the 7,000 are still employed (7,000 minus 29%) we find their total annual earnings are $24,645,000 (5,000 x $4,929), a very substantial sum entering the earnings stream on the side of self-support for these persons.

A further significance of this effort is that as the educational level and expectations rise, fewer people are satisfied to perform simple, menial tasks. By utilizing the retarded, we can act to fill this urgent and basic employment need.

Since our research and demonstration program began in 1955, we have funded (as of December 31, 1969) 105 research projects dealing with the vocational rehabilitation of mentally retarded clients. In addition, we have funded 46 Selected Demonstrations of Occupational Training Centers for the Mentally Retarded, 26 Selected Demonstrations of Coordinated Programs of Vocational Rehabilitation and Special Education Services for the Mentally Retarded, and 8 Selected Demonstrations of a Work Experience Program for the Mentally Retarded in Their Last Year in School. The selected demonstrations were, of course, based on successful prototypes and the services they embodied were expected to become part of ongoing programs.

Our research has been heavily applied and very practical and vocational in thrust. All of it has dealt directly or indirectly with ways and means of making the mentally retarded productive – all the way from competitive to sheltered employment, and from independent living to better self-care in residential centers. Thus, **all of it has been concerned in one way or another with economic payoff.**

The three groups of selected demonstrations (80 projects in all) have had a direct educational, training, vocational, and placement thrust, and the services and programs they demonstrated have been extensively adopted as permanent activities, which multiplies the economic return from our efforts.

It is instructive to note the major areas of concern of the 105 regular research and demonstration projects:

Area of Concern	
Development of comprehensive vocational programs for mental retardation clients, based on assessment of their needs and available community resources (includes 3 projects on their employment in Federal Civil Service)	25
Evaluation of personal, moral, social, educational, and vocational characteristics and development of related special training	25
Test development plus study of other vocationally predictive factors	14
Residential centers and halfway houses	6
Design and use of facilities for the mentally retarded	5
Films	5
Analysis and testing out of specific jobs for the mentally retarded	4
Total	84

Other problems have included attitudes toward the mentally retarded, research needs and the development of better research, longitudinal vocational followup, parental contributions, training of volunteers to work with the mentally retarded, vocational rehabilitation role of the university in working with the mentally retarded, using industrial training resources, training their work supervisors in industry, placement, recreation, habilitation of mentally retarded clients (many projects have had this aspect since many or most mentally retarded clients have never worked before), social training and development, practical training in independent living, varieties of sheltered employment, and production of a mental retardation resource handbook. It would probably be hard to find another research and demonstration program so heavily and directly oriented toward vocational betterment and economic payoff for society.

Further, the cost of all this research has been relatively modest, as shown by the amounts spent for the mentally retarded each year since our programme began. This ranged from $48,700 in 1955 to $3,090,000 in 1965, to $880,000 in 1970, a total of $19,749,698.

The number of mentally retarded clients being rehabilitated by the State vocational rehabilitation agencies during roughly these same years ranged from 106 in 1945 to 26,762 in 1969.

During these same years the percentage of mentally retarded in all clients rehabilitated by the State agencies increased from 0.3% to 11.4%. It is also a fact – though it may of course be a coincidence that soon after our research programme got well underway the number of mentally retarded clients rehabilitated began to increase markedly.

This brief review of our research and demonstration efforts on behalf of the mentally retarded does not purport to establish the economic returns from it in a strict cost-benefit sense. It does make clear, however, that the research done has been very practical and vocational in orientation, that the selected demonstrations were intended specifically to infuse better practices into ongoing programmes, that the research and demonstration cost itself was very modest, and that the number of mentally retarded clients rehabilitated began to increase rapidly soon after the research got underway.

My presentation may differ to a degree from some previous writings in the field of mental retardation. Fernald's (1919) study of persons who had been released or had escaped from the institution he supervised showed that some retardates could indeed adjust to the outside world. This was a great shock to the pessimistic view then prevailing, which strongly emphasized heredity and the need for institutionalization. Other early studies also refuted the notion that all mental retardates are incapable of community adjustment.

A number of surveys done in the years 1921 through 1942 of adult mental retardates discharged from the institutions reached fairly optimistic conclusions on their vocational adjustment, especially after age twenty-five, but of course noted the need for family or professional supervision, the misfortunes they suffer in recessions, and the fact that they tend to be just as deficient in manual as in mental dexterity. But many studies were overly optimistic in their interpretations.

Studies since 1960 have been more sophisticated and challenge some earlier conclusions. Windle's (1962) and Edgerton's (1967) work on discharged institutionalized mental retardates is especially informative.

Of Windle's 356 subjects, 211, or about two-thirds, were failures, mostly because of inadequate interpersonal relations and a variety of anti-social behaviours.

Edgerton studied 110 mentally retarded persons with average IQs of 65 and age of 35 who were able to remain in the community. Forty-eight of these within a fifty-mile radius of the hospital were studied intensively. They were the end product of a long selection process and had finally "made it". Yet they were at the extreme lower end on almost all social and economic indices. They were slum dwellers, marginal economically, had major debts, no job security, and few skills. The most salient finding was that almost all (45 of 48) depended on "benefactors" to maintain even this marginal adjustment. Thus, institutional life did not prepare them for life in the community.

Heber also reports research showing that mentally retarded graduates of special classes do only somewhat better – while a majority may work, their earnings are at the poverty level (perhaps $3,300 a year) and their social and occupational adjustment is not as good as that of non-mental retardates living in the same neighbourhood.

The more complex the society, the harder it is for the retardate to adjust. It was easier for them to adjust in Fernald's day.

It is likely that many in the social welfare field underestimate the human importance of economics and business out of a desire to avoid giving undue weight to anything so crass. This is less true of rehabilitation, which from its beginning has had to fight its way forward against prejudice by demonstrating the **economic** as well as the human gains from rehabilitating the handicapped. Unfortunately, we have not until recently given much formal attention to economic factors, and may over the years have gathered too little "hard" data on the good economic effects of our programmes.

"Who steals my purse steals trash" is true only in context. A truer (though more prosaic) rendition would be "Who steals my purse steals every humanly important good that its contents would buy" – and money can clearly buy many items of great human worth.

If we wish to visualize a process of dehumanization, we have only to imagine a person imprisoned and deprived of all clothing and similar amenities, starved for food and sleep as well, and perhaps otherwise physically inconvenienced also. This has happened in modern times, and dramatizes the importance of the economic realm and of physical possessions to man. As William James said in speaking of the material self, it is the body, but more than the body. It includes clothing, house, property, and bank account – all the possessions the self can call its own. When they flourish and prosper, they bring elation and a sense of triumph; when they diminish or die, they bring dejection and depression, and a feeling of "partial conversion . . . . . to nothingness".

Thus, without invoking the radical's cry that man's whole ideology and value system are economically determined, we can still emphasize the need to take economic factors very seriously, man being what he is. More importantly, we can point to the choices we have for our investments in human beings. Hopefully, the point of this paper has been the fact that those choices which are economically most rewarding are those which emphasize most the dignity and worth of the individual.

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FORMAL OPENING

OF THE

FIRST CARIBBEAN MENTAL RETARDATION CONFERENCE

by Hon. E.L. Allen, Minister of Education, Jamaica.

This year is recognised in Jamaica as International Education Year. We tried during this year to give some stimulation to all aspects of our educational effort, to do some stock-taking, planning, to set new horizons, and aim at new objectives.

Last week, I dealt with early childhood education. At other times during the year I have had to deal with the education of the blind and the deaf. During the summer holidays, a good percentage of our teachers were attending one type of in-service training course or another. Now, as a sort of very fine climax we have this gathering of renowned and distinguished educators, pyschologists and medical personnel from some Twenty-six countries assembling here, for the purpose of considering the welfare of the very important group of handicapped people in our various communities.

I want to thank the organisers. I feel that every person who has assembled here is likely to go back to his country the richer because of the contribution of the delegates from the twenty-five countries, who will pool their knowledge and experience, their hopes and their aspirations. Ladies and gentlemen I wish to thank you for coming. As representative of the Government of Jamaica, it is my duty to say how pleased the Government is to have your presence here with us. We sincerely hope that in between the rich and profitable discussions which will take place, you will find a little time to tour our island, to take advantage of facilities that we have to offer and to enjoy yourselves thoroughly.

We, on our part, are extremely pleased to have you. We share in your aspirations as regards attention to the handicapped. Here in Jamaica, because of economic circumstances, the care of the handicapped is merely subsidized by the Government, and is largely dependent on the work of public spirited people, professional people as well as other members of our community. When I compare our feeble contribution with the astronomical figures of the expenditures in the United States, well, I really felt that you did well to have seated me on the floor! However, I wish to say that our Government is interested. During this very week we hope to declare open a new building, constructed largely by funds raised from private sources, to accommodate 100 children. That's a small fraction of the mentally handicapped children in Jamaica. There are some scattered in our schools, chiefly our primary schools. I wish to inform you that we are in the midst of reforming the entire educational system of Jamaica. Two of the types of schools where we hope to and are actually doing work on, are the primary and Junior Secondary schools. We hope to have teachers specially trained to deal with retarded children and slow learners and to develop this kind of pedagogic skill among our primary school teachers, so that in every primary and Junior Secondary school in due course, there will be skilled teachers, specially trained to deal with this type of child.

In Jamaica we have much to learn from you and we are willing to do so. That's an additional reason why we are happy to welcome you, and having said this, it gives me very great pleasure to declare this conference open.

SESSION I

The Pre-School Period

Plenary Session: Topic 1

"The Identification and Assessment of Mentally Retarded in the Caribbean."

by Dr. Geoffrey Woo-Ming, M.B., B.S., M.P.H.
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September 7, 1970

The full title of this paper reads "The Identification and Assessment of Retarded Children in the Caribbean" – and I do believe "in the Caribbean" to be the most important operating phrase – so that above all I shall endeavour to remain relevant to Caribbean needs and suggest approaches compatible with Caribbean resources – both real and probable.

Dr. Garrett gave us some of the reasons why – I would like to set the stage for discussion of who, when, how, by whom and for what. In doing so it is possible that I may bruise some professional sensibilities for which I apologise in advance, but you will remember that I am speaking purely in the Caribbean context.

First of all we should decide who are the children we are interested in identifying. As most of us know, estimates of mental retardation incidence vary from 2% in affluent areas to 7% in deprived regions, with the usual conservative overall figure of 3% being mentioned. In Jamaica this would mean 60,000 affected individuals with 1,800 being born every year or five every day.

Eighty to eighty-five percent of these would be classified as mildly retarded in the United States or ESN in Britain, 10% – 13% as moderately affected or trainable, and the remainder as severely or profoundly mentally handicapped. In the Caribbean it is probable that the mildly retarded go through the regular school system and most of the facilities designated for the mentally handicapped are for those moderately and severely affected. Therefore it stands to reason that the identification of the mildly retarded in the Caribbean might be justifiable only when special intervention resources to meet their needs become available either in the educational system or in the first two years of life, If, however, present methods of assessment can identify those children who are mildly retarded due to a depriving environment during their first two years, it is possible that appropriate intervention might halt and even reverse this type of mental retardation.

Having determined one target group as predicated by our national priorities, we should decide the time in terms of mental development when this should take place. With limited resources, initially we might have to concentrate on those periods that have been most fruitful for previous investigators – even including the antenatal period, for it is now possible to diagnose a foetus with Down's syndrome at 12 – 16 weeks of gestation – which has obvious implications for prevention.

If we are planning to commit resources for early intervention in the hope of reversing environmental retardation to some extent, the emphasis should be on the early years. If we intend to evaluate mainly for educational placement, and concentrate on the moderately and severely handicapped, an older age group is indicated.

Next we come to the ticklish question of who will be the people to carry out these assessments. With due apologies to the disciplines represented here, it seems that this should depend on the goals, the age of the subject, and the professional resources available. For early screening to detect children with slow development or with a high index of environmental deprivation, in the Caribbean as elsewhere we may very well utilise the persons who are already seeing the children. These are health visitors and public health nurses – with suitable training in child development. Alternatively community workers may be trained with a general degree of helping skills, among them simple techniques in spotting developmental delay in pre-school children.

If we are not interested in active screening and case-finding, for the pre-school ages our first priority then should be to acquaint the physicians in practice of various developmental screening tests easily carried out in their offices that would indicate the need for more precise evaluation. It becomes a medical problem because it is to the physician primarily that the public looks for advice and diagnosis.

For the school-aged child, in order to expand the efficacy of the few psychologists in the Caribbean, perhaps these few may be willing to instruct interested teachers to administer a few key procedures such as the Stanford–Binet or the Wechsler Intelligence Scale for Children. To do this will involve for some the breakdown of traditional disciplinary barriers and jealousies.

Two other types of evaluations for the retarded child-vocational and social assessments, will have to be developed later, as necessary corollaries to preparation for appropriate training and life in the community. These should go hand-in-hand with improved perception of the needs of the retarded in the educational system. These may well be the responsibility of rehabilitation counsellors, teachers or social workers.

In terms of traditional medical procedures involving blood and urine that will detect treatable causes of mental retardation such as phenylhetomina, hypothyroidism, hypoglycemia and galactosemia during the neonatal period, at the present time it is doubtful whether recognition and treatment of these conditions will have a significant impact on mental retardation in the Caribbean; although of course, we have no data on their incidence at present.

What is vital, though, is that physicians who see children during the first two years be alert to the possibility of hearing deficiency, since this is a not uncommon cause of slow development and apparent retardation that is potentially remediable.

We can now briefly discuss some selected screening tests and more elaborate procedures available that could be modified for Caribbean use. Some were devised by pediatricians, some by child psychologists but we should not let origin prejudice their use. The Denver Developmental Screening Test was devised in 1967 and emphasises the first 24 months after birth in 4 areas – gross motor, fine motor and adaptive behaviour, language and personal-social activities. It is well standardised and easy to administer and score, taking approximately 20 minutes. One distinct advantage is that it give percentile figures with a range of norms so that an estimate of both precocious and slow development is obtainable in terms of standard deviations. It appears ideally suited for para-professional screening of young infants, but of course it may be necessary to confirm or develop Caribbean norms. The Ammon-Quick test is designed for ages 3½ through adulthood and is based on the understanding of language concepts. It can be also administered by non-professionals after minimal training and takes about 10 minutes. It consists of three sets of four pictures and the subject is asked to identify the picture which corresponds to a given word. It increases in difficulty – thus for picture (1) it goes from dancing to graceful to cordiality to amicable.

Unfortunately, this was standardized for white American children and adults, so again norms may have to be readjusted or even new words substituted. The Peabody Picture Vocabulary Test is similar but more comprehensive. The "Draw-a-person test" is well known but again has not been standardized in the Caribbean, although it is possible that it is fairly culture-free.

For more comprehensive evaluation, the Bayley Scales of Infant Development was restandardized in 1969 on 1,200 children throughout the United States between the ages of 2-30 months, approximately 15% of them non-white. Testing time is approximately 45 minutes to 1 hour and consists of mental and motor scales with a record of infant behaviour. At the present time it appears to be the instrument by which it is possible that small decrements in development may be detected. Again it appears suitable for administration by properly trained para-professionals with a high school education.

Special procedures such as the Leiter Performance Scale and Raven's Progressive Matrices are non-language tests for children with verbal handicaps. Other commonly used tests such as the Illinois Test of Psycholinguistic Abilities, Stanford-Binet and the Wechsler Intelligence Scale for children, are suitable for older children, provide IQ numbers, and are much used in educational placement. Caution is necessary in their interpretation, as problems in communication, behaviour motivation and the environmental situation must be taken into account – this usually reflects the experience of the examiner. When estimates of social skills are needed, the Vineland Social Maturity Scale is useful, but may be replaced by the more comprehensive and well-standardized A.A.M.D. Adaptive Behaviour Scale made available this year.

There are over 1,200 more psychometric tests iisted – and those that are new are not necessarily the best. I am suggesting that for the Caribbean area, a number of procedures should be developed for our own use and to start with we should probably use well-standardized and proven tests that appear applicable to non-white lower-class populations.

It appears somewhat trite to say that it is important that the assessor should be clear as to the aims of the evaluation, but it is remarkable how often assessment is a means of case disposal rather than case management. If a test is merely utilized to reinforce an intuitive feeling about a child, and the results ignored if it does not conform to the opinion of the examiner, then either the test was inappropriate to begin with or this is a clear case of psychometric malpractice!

Another truism is that meaningful and feasible recommendations should arise from the evaluation, and an attempt made to help the parents follow-through on these recommendations. This implies that community resources should be developing concomitantly with case finding and screening activities – otherwise the resulting frustration will nullify any progress being made in identification and evaluation.

In summary then, it is proposed that developing countries such as in the Caribbean, need to determine their goals and priorities with respect to the mentally retarded in the light of the experience of other countries, so as to maximise the impact of available resources.

We need an estimate of the extent and nature of the problem, and to develop norms for psychological tests that appear relevant to the people of our region.

With our limited professional resources, we need to explore innovative ways of utilizing the personnel we have at all levels, and, if necessary, to train new categories of para-professionals to close gaps in the services for the retarded. In doing so, we will have to ask the cooperation of many disciplines, especially medicine and psychology, to lower traditional disciplinary barriers and loosen some of their closely guarded prerogatives.

The fact that we are here today in such numbers makes me believe that such a future is not only possible but downright inevitable.

Discussion

"The Identification and Assessment of the Mentally Retarded in the Caribbean"

Chairman: Dr. Henry Podlewski (Bahamas)
Reactor: Dr. Frank Williams (Guyana)

Dr. Williams:

Dr. Woo-Ming as a Guyanese, is well aware of the general situation in most of the countries in the Caribbean. For instance, we don't prevent all the preventable diseases, we still have children dying of malnutrition, tetanus and diphtheria. As I understand his paper, he is making a plea for a very early start in the care for the mentally retarded, a plea for prevention in that if we had them two years earlier, then hopefully we would not end up with such a large number.

Where do we start? Do we write off the present mentally retarded having regard to our financial resources, and concentrate on the area of his paper? Do we spread out our resources and do a little bit with the older ones and a little bit with the younger ones?

Dr. Woo-Ming:

I meant when I said that we are going to have to develop national priorities that unfortunately we might have to make the best of a bad situation. Preventive measures are more economic than curative measures. Maybe we could develop a small scale pilot project in which children had a change in their environment compared with a control group. This might show Governments that it was an economically feasible proposition.

Dr. Thorburn (Jamaica):

Could Dr. Williams tell us how you go about identifying cases of M.R. in Guyana and what you do with them when you get them?

Dr. Williams:

From 1960 we had discussions and plans and in 1968 a school was built in Georgetown to provide for the deaf, blind and M.R. We put ads in the paper for children aged 6 - 12 years and saw them in Sunday morning sessions. There were several paediatricians, occasionally a psychologist, the nun who was running the school and Lady Rose, the wife of the late Governor General. Our screening and general approach is necessarily a rough and ready thing. It depends on the mother's history, observation of the child and doing very rough things like "Draw-a-man", drawing circles etc. This was how we started.

We are doing nothing with the earlier age groups. There are also a large number of ESN children whom we cannot deal with. These are referred to the Ministry of Education. We are about to start a sheltered workship this year from funds from the International Red Cross. But we are very short of teachers.

Dr. Bijou (Haiti):

The problem of mental retardation can not be evaluated exactly in Haiti, because it is a neglected problem, since the mental health technicians are overloaded with problems, and the mental

retardation area does not seem to be a rewarding one.

For the whole population (about 5 million) there are only five psychiatrists and two psychologists.

Our only public centre of active psychiatric treatment cannot evaluate and classify mentally retarded children since it has nothing to offer as far as treatment is concerned. Furthermore the only psychologist attached to the institution works part-time (one half day a week for children). Therefore it would be materially impossible to test every child suspected to be mentally retarded. We need then simple tests that can be administered and interpreted by anyone with a short training (psychologist aid or something of the kind).

There are two special schools: one is for people of the middle and upper classes; it accommodates twenty children and mingles mentally retarded, emotionally disturbed, dyslexics, etc. The other one, which is non-profit, can accommodate about the same number; it would like to help only true mentally retarded children (slightly and moderately retarded) from any class of family. To select them we use only life history and clinical examination without elaborate psychological tests; we do not even have a psychologist attached to our institution.

One psychologist working only in private told me that for the past two years she has been taking three retarded children at her office for rehabilitation. Her selection is made only of slightly retarded. She is not interested in the moderately, severely or profoundly retarded Her attitude is understandable.

Now the "Institute Medico-psychologique Dyna" of which I am the director-co-ordinator would like to find:

1) A simple economical way of testing the largest number of apparently retarded children. (What about the standardization of the tests?)

2) A simple and practical way of classifying them.

3) Some tips about their rehabilitation with rather limited resources in money and trained personnel.

Professor Delia Lugo (Puerto Rico):

I was going to comment on what we have been doing in Puerto Rico for the assessment of children who seem to be retarded. There is a diagnostic centre in a central part of the metropolitan area, and we have gathered there four or five psychologists, pediatricians and some nurses and teachers. This centre takes care of the cases that are referred from the schools, health centres and everywhere. They have been able to help the public schools a lot.

When there is a public school with a lot of learning troubles, they ask the centre to move to the district. They go for about a week and assess the children. This has helped a lot. Even so, we know it is not enough. There is a suggestion that more persons should be trained, and I want to ask now what type of personnel will these be, because I work with the training programme, and I would like to know what type of students, who could train them and how. How could we do this to improve the services offered?

Dr. Woo-Ming:

I have been fortunate to visit several centres in the United States and I think one of the main barriers to utilizing paraprofessionals has been opposition by the various disciplines, especially medicine and psychology. But the latter are either few in number or overworked in the Caribbean.

Now this is the Denver Screening Test. I did not bring the actual kit, but it consists of simple things like raisins, a bottle, a bell, blocks, very simple equipment. Really you don't need to have a Master's degree in psychology to use this as a screening device.

If you are trying to deal with large numbers of children and you have one psychologist in the island, obviously you shouldn't be putting this psychologist to doing this.

A lot of the test items are things that I believe would be the same irrespective of language – knows his name; recognizes objects by name. This was developed by a psychologist, but it seems that this is the sort of thing that we could be developing on our own, based on our own local culture. Similarly there is the Nancy Bayley for two to twenty-four months age group. Now the Ammons Screening Test is a verbal test and obviously if we have notable language differences it will have to be modified but it ranges from 3½ years up.

Dr. Neehall (Trinidad):

I have been doing some evaluation studies on adults with the Ravens Test, and the results so far are very encouraging. I don't know if it is being done in any other islands. I am wondering if it would be worthwhile extending this study to normal children of a younger age group. It is necessary for us to establish norms before we start talking about identifying the retarded.

Mother Joan Teresa (Trinidad):

Do we really know the range of normality? I have found in connection with the problem of identification of the mentally retarded that very few of our medical practitioners really do understand the range of normality. Eighty percent of our mentally retarded come within the educationally sub-normal group. This seems to be our biggest problem. What we call the medium grades loosely, are fairly easily recognizable. But with the mildly retarded, when parents go to medical practitioners about behaviour problems and such things they say "Oh, this child is perfectly normal. He can continue in normal society. Go ahead and send him back to school." They prescribe a few tranquillizers and he goes back. This is the type of child who eventually finds himself in an approved school or an institution for the mentally retarded.

In the large colony where I worked in England this was the case. It was immaterial whether the child committed some misdeed, came before the courts for pilfering or for some other offence, he was either sent to a residential school for the mentally retarded or to an approved school.

I think that our assessment services really need to be updated in this respect. We have close liaison with an approved school, and we find that we have often got referrals from there. Eventually we find that with correct assessment, behaviour problems begin to be resolved in this other setting, and the child begins to learn because he is with his peer group.

This is an important category. We need ways and means of correct assessment along these lines.

Dr. Williams:

I can't agree with Dr. Woo-Ming that there is no point trying to identify the educationally sub-normal, because we have no

means of dealing with them at the moment. I think it is important for us to identify the problems, to identify the needs of the community in order that we could make proposals to the Government.

We very often blame our governments for things which we are really to be blamed for. We expect them to make plans which work. But for effective planning they must know what the needs are. We are the ones to determine that, write papers and inform our governments. We cannot wait for the government to provide the resources for the educationally sub-normal, then determine the extent of the problem.

Mr. V. Serritella (Jamaica):

Our association for deaf children saw over one hundred children in 1969 that were mentally retarded.

It is totally naive to develop a school system for children with handicaps without knowing how many there are, when they were born, etc. Total outlook in other words.

I am also greatly concerned about who is going to do the assessment. In the Caribbean the doctors have the main responsibility. In Jamaica they are tremendously overworked. I work with them every day. Our public health nurses also are tremendously over-worked. I urge West Indians to develop possibly a radical system of identifying these children, using community workers, if there is such a thing, with spare time. Using teachers, which our association uses primarily in identifying children. To say we are going to be using doctors, when we know our doctors are grossly over-worked, I think is sticking our proverbial heads in our proverbial holes.

Dr. L. Wynter (Jamaica):

As a paediatrician I find that everybody passes the buck. I think that as soon as you are certain of the diagnosis the parent ought to be told in a gentle, calm fashion so she is prepared for what she has to expect. I would like to appeal to people who deal with the training of doctors to point out to them what normalcy is, because if you don't know what is normal then obviously you can't tell what is abnormal.

Elaine Golding (New York City):

One of the main problems with psychologists, psychiatrists and medical people is not using the resources of the teacher to the extent that they could. Teachers are still the best prepared to make a statement about ranges of intelligence of children. Not in terms of I.Q. points, but how the child functions. how the child relates to others.

In New York what we have been trying to do is assess where the children are rather than worry about what's wrong or what's sub-normal, but see just what is that child's individual pattern of learning, then fit the programme to the children.

Dr. Feldman (Jamaica):

I am very keen on the idea of a multi-disciplinary approach. I think we have got to come out of the ivory towers and learn to communicate with one another.

Now since I worked in the Child Guidance Clinic I have been fortunate enough to have the co-operation of a paediatrician, Public Health nurses, an educational psychologist and a speech therapist. I feel this is vital to a Child Guidance Clinic, and this is a very excellent medium through which this type of co-operation could be formed, of a number of disciplines.

Mrs. Mary Charles (St. Lucia):

I get a bit anxious when I hear comments such as this. Often the little islands, St. Lucia, St. Vincent, St. Kitts, Nevis don't have paediatricians, may not have social workers, may not have occupational therapists and so on, tend to feel that they have been left behind. I should like to refer to Dr. Bijou's question earlier when he said, "these islands are looking for simple means of assessment, simple means of identification, so they can begin to establish some type of programme."

Mr. A. Odle (Antigua):

I wish to endorse that. In Antigua there is no programme for training the mentally handicapped. I am the manager of the mental hospital, and I am the representative of the Ministry of Home Affairs and they expect me on my return to bring back to them a programme. Something that will be satisfactory, that they may be able to subscribe to the opening of a school for the mentally retarded.

In the mental hospital we have had between the years 1960 to 1970 approximately thirty admissions – mentally retarded. They reach the mental hospital as other problems. They come in as depressives and so on. They are now out with the exception of three.

You can also find the mentally retarded in the home for the aged. I paid a visit there and it is deplorable. But, I am hoping to take back some knowledge home when I finish this conference.

Dr. Thorburn:

We have been trying out the Denver Development Screening Test here. In Jamaica we have a very sort of scattered approach to mental retardation. There are people seeing cases here and there, we have paediatric clinics in the two hospitals, also at Bellevue Hospital and the Child Guidance Clinics. We also have cases who come directly to the Association for Mentally Handicapped, because they have already been diagnosed.

Now the present procedure is that cases that are referred to the Association are referred to a panel of doctors. I have been using the Denver Test and I have found it very valuable. We think we can tell whether a child is moderately or severely retarded. It also tells us whether the child is sort of on the upper borderline, but it does not tell us how good a borderline child is.

We have a problem with children say of the age of ten or twelve who pass the test (which goes up to the age of about six), but their performance at school suggests that they are retarded. This is where we need a psychologist's advice, because we cannot evaluate them sufficiently. If they are good enough to remain in the school system then we don't want to have them in a special school for retarded.

The limited experience we have had with this test has been quite helpful. In Jamaica we are a little better off than some of the other islands. We do have one or two psychologists, paediatricians who are interested and we have social workers. We should have a much more combined approach. We ought to have some sort of centre, even if it is only two mornings a week. We should be working in collaboration instead of working in all sorts of different places.

Dr. Podlewski:

You might like to hear about the Bahamas, but first of all I

should like to dispel your possible notion that these islands are inhabited by millionaires only. On the contrary, we have a good share of poverty, and we have a colossal number of problems. Until very recently we did no have any psychologists. We have contacted a clinic in Fort Lauderdale which has a voluntary basis. There are offers to come at regular intervals and do screenings for us. For about two or three years this was done.

Miss C. Hanna (Bahamas):

We in the Ministry of Education were very concerned as to the number of retarded children so that additional provision could be made for them.

We have a school for the retarded that accommodates some 40-45 children. In this survey we got the co-operation of all the teachers in all the schools throughout the island. Also, we had the co-operation of the hospital, paediatricians and social workers. We worked out a very simple form, whereby a teacher who had no psychological knowledge can easily identify children for screening process. This consisted of about ten simple questions.

These forms were sent to Nassau and to some twenty-eight other islands. The forms were collected and a team of specialists involving the two psychologists on the island, the psychiatrist and a number of other people, did a simple pilot scheme. They went into the schools and tested a number of children using the Bendiger Gestalt and the "Draw-a-man".

Screening for each child took less than ten minutes. Also the teachers were asked to give a detailed description of the performance of children in the schools. The report is in the final stages of writing, but we can say right now that some 3-4 percent of children in our normal schools are retarded.

It is a policy of the Ministry of Education now to have these children in the normal schools as far as possible, and only those who simply cannot cope will not be in the ordinary school.

Dr. Podlewski

I think it should be possible on the islands which have no professionals, by using these simple criteria to get a list of children, and then perhaps we could have some sort of scheme of visiting teams of specialists who could follow it up.

Dr. Williams:

I am wondering whether we have not reached the stage, Mr. Chairman, where we ought to discuss a regional approach to these problems – to define what is normal and what is abnormal, isolating the language problem in terms of assessment, because I think most of us in this region face the same type of problem. Also a regional approach to the training, not necessarily to the high-falutin' and high grade training that we all seem to think we need, but the sort of training which Dr. Woo-Ming has been talking about.

Professor Lugo (Puerto Rico)

I think we could contribute to that too. This team could train personnel, and I feel that teachers are the people that could be used for this purpose. So the team could be the trainers and the teachers could be used and the programme could be solved in part at least.

We don't have this kind of training in our teacher training programme, but we could incorporate it to improve the training of the teachers, so that they could help in the assessment.

Dr. Williams:

I think we need a central area in some territory that is studying the whole problem in the Caribbean, and then your team moves out from that central area into other places where the whole problem is studied, the problem of assessment at various age groups, the problem of utilizing the maximum number of people.

Dr. Woo-Ming:

I would like to add a word of caution about travel teams. When you are bringing in outside expertise very often the expertise goes when the team goes. The travelling teams in the States found that the people who were the recipients just sat back and let them do everything. We must be sure that we have local commitments and backing and we really know what we are trying to accomplish.

Mr. Marion Smith (U.S.A.)

I should like to inject into the discussion the consideration of the people most concerned – the parents, and submit the concept that in making your plans to improve the situation in the Caribbean, that you involve them.

We have found in our country and in other countries, that we emotional parents, once we bank together, will demand those services from our government groups, from our various federal agencies and those involved. We will vote for the actions that are needed to cause these services to be placed in our community, both the residential services and the educational and the training services. So I would suggest that in considering a regional approach, consider the establishment of an association for retarded children and adults in each and every territory, country and island, and use that as an action and focal point and it will accelerate yourprogress.

Dr. Mazet (Guadaloupe):

Dr. Mazet wants to endorse this. He thinks that since the parents are the persons most concerned, they should be considered seriously in any team or any programme. In Guadaloupe if there is an association of parents wanting to do something, according to the law, they would find resources.

By grouping the parents, you would give them some moral support. This would prevent another problem, discouragement, when they come for evaluation. If your resources do not permit you to do anything as far as rehabilitation is concerned, by grouping them you have already done something, by giving some moral support.

Dr. Thorburn:

We have heard that there are a lot of places where people don't know whether the children are retarded or not. The problem in many of the islands is that there is no one to tell the parent that the child is retarded, and there is no parent group until the children have been diagnosed. Our experience here in Jamaica is that we have had a Jamaica Association for a long time, but it needs a lot more professional involvement. Parents cannot do anything on their own. It can fizzle along for years.

Miss Hanna:

I would just like to make some comments about public education and what we have been doing in the Bahamas. We have an association for mental retardation. Each year we have a health week and last year we highlighted mental retardation. Our main object in this was to get the public aware. We ran a series of radio programmes and newspaper items, and we had simple pamphlets printed. Also we had posters that were very simply illustrated.

The Ministry of Education has been giving a series of programmes on mental retardation, how to identify the child, and I am particularly involved in remedial education. The parents and friends of mentally retarded children identified with this programme, and they were asking us to do more and more.

We are beginning to make some progress in this way. So perhaps you can use the same media. Radio, newspaper, pamphlets. Also when I go around to the schools I ask the teachers, "Would you like someone to speak to your parent group about mental retardation?" So I have been going around talking to them and other people in education, and in the Psychiatric Hospital.

Dr. Podlewski:

It seems to me that some sort of standardization of test is necessary if we are to compare our work and our problems. There is, of course, WHO Diagnostic Classification, which I think has been approved by the American Psychiatric Association.

Professor Lugo:

How can you do that if you don't have the personnel to give the test, so I think we have to start with training some personnel.

Mrs. Charles:

I think it has already been established that we do not need professionals to administer these simple tests. If the areas which do not have the psychologists or the psychiatric social worker and so on have a simple means of testing these individuals, and they eventually have a group who could meet with a visiting team. Because of the small islands being unequipped with professional persons, this does not mean we have to wait until we get professionals. We can begin with the resources we have. I think that what we want are simple tests which can be administered by teachers, nurses and the like.

Dr. Neehall:

I would like to make a plea before we end. Since the Denver Developmental Screening Test has been found to be so useful in Jamaica, I would like to suggest that we standardize it on a regional basis.

Dorothy Dale (Jamaica):

I was wondering whether those of you here who are experienced with the Denver Test would say that somebody like myself, a social worker, could administer the test. It seems to me it may be a few years before a regional team gets off the ground and I am terribly interested in doing something here and now, because we have so many children that we are so concerned about, and we are not able to help them at all or even recognize what the problem is.

Dr. Woo-Ming:

I think that it will take you as long as four hours to know how to do the test.

The Denver Test and the other one that I brought is particularly useful, because we could roughly determine present mental functions, and then we could say that if their functioning is greater than half their chronologic age, then they would fit in the EM or ESN type of thing, or mildly retarded, and if they are functioning below that level they would be in the TMR or the moderately retarded.

It really goes up to about age five. The Peabody language test is probably very useful for educational purposes for children who are older. It was standardized on white American children, but really it is just a series of pictures in which you determine various language concepts. This can be standardized for the West Indies. This can actually be done in about ten minutes. We are using this for paediatric residents in the hospital who have school problems referred to them. But you don't have to have medical training to do this. All you need is just to repeat the word and the child points to the correct picture and you score it. And then you just add it up. It is extremely simple and I think the principle is right for the West Indies. The words may not be right, but this should be a minor problem.

It is also very important that you get the manual that goes with the test and that we don't all become instant psychologists. Bear in mind that it is a psychological test and that it is a screening device. We have got to make sure that it is standardized because you cannot really just use that sheet and go ahead.

Dr. Thorburn:

A point which has developed out of the idea of having a regional body as Dr. Williams has suggested – there seem to be about three or four places in the Caribbean – Puerto Rico, Bahamas, Jamaica, Trinidad – who have quite considerable personnel compared with some of the other islands. We should be able to organize one or two people from Trinidad or Puerto Rico to go to an island and get together a group of social workers, teachers and so, who would have to be organized by the representative in that particular island, and give them instructions on the use of these tests.

I see that we would have to have a regional body at the centre of this with main area responsibilities. Every island should have a representative who would co-ordinate and bring in the people from their own area, who they think would be interested enough and able enough to want to do this. In this way we could incorporate para-professionals. Obviously the local association for retarded, if there is one, would be the contact point.

One of the main problems is the question of money. How would a regional body be financed? It is quite possible that people from North American countries may know some body or source which might be interested enough to sponsor such a centre: a Caribbean Institute of Mental Retardation, or something similar.

RECOMMENDATIONS

1. There is a need for a co-ordinating centre to collect information, provide advice, provide a team of advisers and trainees who might go out into the undeveloped communities and conduct training courses for personnel there. Expert psychological advice of people well versed in the area's culture should be used.

2. There should be 3 or 4 sub-centres who would give assistance with personnel from e.g. Trinidad, Jamaica, Bahamas, to the immediate surrounding area.

3. Each island or country should have a group through which any programme would be co-ordinated.

4. The co-ordinating centre should conduct research into the development or adaptation of psychological and development tests suitable to the Caribbean and its culture and developing standards of norms.

5. It is recognised that such a centre, a "Caribbean Institute for Mental Retardation" or a co-ordinator would require substantial funding, which would have to be investigated.

Sources of Tests Discussed

Denver Developmental Screening Test	– Mead, Johnson
Ammons Clinical Test	– Psychological Test Specialists
Bayley Scales of Infant Development	– The Psychological Corporation, 304 E. 45th Street, New York, N.Y. 10017
Peabody Picture Vocabulary Test & Vineland Social Maturity Scales	– American Guidance Service, Inc., Publishers Bldg., Circle Pines, Minnesota, 55014

SESSION I

The Pre-School Period

Plenary Session: Topic 2

"The Pre-School Environment and Mental Retardation"

by

Dr. William A. Hawke, M.D.

Professor of Developmental Medicine,
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September, 7, 1970.

I would like to review a study that was made over a three year period on children born between March 15 and April 15, 1967 at the University Hospital of the West Indies. The children were seen annually at the time of their birthday and were tested using the Gesell test for the first two years with the addition of some items from the Stanford-Binet in the third year. The collaborators were Professor Eric Back, Dr. Sally MacGregor and Mrs. B. Williams, social worker.

Most children came from the Kingston area and would be classed as lower and middle with a few upper middle class. About sixty children were seen each year. As some dropped out, a few were added in the third year. The final results were not much different for the two groups.

Racially they were predominantly African and a few Indian and mixed. The marital status was 40% single, 31% married and living with husbands and 24% common-law, or married but not living with husbands.

The nutritional status was generally good with no gross deficiency. A few with low haemoglobins were mostly found to have sickle cell anaemia. Their development was almost identical to the rest.

We tested for gross motor skills (including walking, climbing, stairs, kicking a ball), fine motor (involving the upper extremity), adaptive tests which probably represent judgment, reasoning, and the ability to analyse a situation on the basis of past experience. Verbal and non-verbal language ability, both receptive and expressive was tested, naming objects, naming pictures that answer questions, etc. Personal/social testing included relationships to family, eating, feeding, toilet training etc.

Results

In the first year scoring was in the normal range, with a relatively high gross motor performance.

In the second year it was largely normal but with perhaps a slight drop in language, the significance of which is uncertain. By the third year the scores had begun to drop especially in adaptive, judgment and language skills. I believe these were significant.

Discussion

Previous studies on Jamaican children tend to support these findings. The Van Leer group did a study on four year olds using an American inventory called the Collvo Pre-School Inventory which had clearly been modified, as the basic language would have been incomprehensible to many Jamaican children. They found that the children were a year behind at four years of age in many areas, a greater drop than we have found here.

Vernon in the United Kingdom compared a group of Jamaican children with English and other cultures. Their highest level of function was in rote learning, and spelling and the lowest areas were language, judgment and creativity. These results suggest that what we have seen at three years may persist as the child gets older.

At this point it is vital that we discuss various factors which may modify the interpretation of the results.

Firstly we are using a test standardised in one culture for children in another culture. At the end of the third year I began to feel that no child in Jamaica loved me, so we brought in a group of five children from an upper middle class, professional background. They were eager, they enjoyed the tests and were cooperative and communicative. They were exactly like the children to whom I am accustomed. This was in contrast to the test children who were slow to get involved. There was much less communication. It was obvious that they were happier with objects and equipment rather than with me. When I began to intervene they were reluctant to perform. It was much better to observe them than to participate.

The girls tended to be more communicative than the boys though occasionally there was the rebel who would be playing off against his mother.

Another factor is probably that young children, especially in the Caribbean, may relate better to females, especially as the male may not be a close figure. My colour was also fascinating to some, as they would watch me before becoming involved in the tests. There was also frequently a language problem and the mother often had to translate for me.

The setting was not neutral. It was an open noisy hospital cubicle. The children had had previous physical and blood examinations there, so there was a certain amount of anxiety. The adults were usually quiet and did not exert pressure on the child – very much in contrast to our culture where the mother is urging the child to perform well. Where the child normally lived with the grandmother and was brought by the mother, on retesting we found a different performance when they came with the person with whom they were living.

Parental responses to questions on some areas (personal and social) were I felt, accurate and honest. Where we were able to corroborate their histories, it came out much as was reported, again in contrast to our culture where mothers tend to give a rosy version of their child's achievements.

The actual administration of the tests had to be modified. If I had used them in the prescribed way (and they are rigidly prepared and structured) the results would have been infinitely lower. For instance I repeated tests, and often the child would do it immediately the second or third time, so you knew he could do it. This was a question of motivating and blocking. We also had to rephrase the language. In time tests, they frequently did nothing for quite a long time then would suddenly complete the test in a short time.

In the Gesell you score for plurals, and very few children would score here. Plurals are almost non-existent in much Jamaican language.

Some of the objects shown e.g. a steam locomotive, none of the children had seen and could obviously not recognise. Similarly, flags and the little star we see in our books, were not recognised. A horse was always a donkey to these children which would be wrong if you were scoring correctly. Again in the case of the telephone, if the child had one he knew it, if not, he did not. We therefore had to restructure the tests using different objects. When retested they scored on the whole 3–5 points higher.

Some of the children where I felt I could not get cooperation and who did poorly later often gave a good performance in the early years, were retested by Mrs. Williams who is a Guyanese. However there was not a major difference in the results. The feeling that we were not testing the children fairly has bothered me throughout.

There was a rather high individual variation from year to year, up to 15 or 20 points. This is not unusual in pre-school groups. Further examination indicated that the major factor was motivation. The child was either resisting or not interested.

Some children who had major drops were retested and some scored better. I felt this was the increased interest and not purely the repetition.

These factors indicate that it is vital to adapt your tests as far as possible to the culture. Standards and judgment of intelligence must be based on local standards and not on the basis of the original standards.

My impression is that we have found a lower rating. This is not gross. We may have leaned over backwards to try and give the benefit of the doubt.

Why should the levels vary? The motor skills may be better because the culture allows more freedom and more opportunities. There may also be a constitutional factor; this is undecided.

There are two possible reasons for the poorer performance in the adaptive tests. One would be the little exposure to books, and stimulating equipment. The other again might be constitutional in that they might not have the same visual and perceptive skills that others have. Variation in the latter may be familial in the Canadian culture, so this question has to be left open.

Language to my mind is cultural. The parent has limited language and communication. The few sibs we tested were also significantly below normal.

To try and correlate levels of development with home structure Mrs. Williams visited the ten poorest and the ten best families. We found about a 4% difference in the adaptive and language tests only, much as we expected. Whether this is statistically significant has not been established.

What is the relationship of these results to intelligence. This is a very emotional topic. I think we were testing intelligence because some children were consistently low and some consistently high. However this particular test is also affected by environment and culture. It may be impossible to devise a culture free test.

However we can say we are detecting absence of skills which may affect education. These deficiencies are going to cause difficulty in learning and possibly a permanent limitation in their future educability. These skills are necessary for modern education and if the children of the Caribbean are to have the education desired for them these skills must be upgraded.

This implies a special educational and remediation programme, which must begin at least by two years of age or maybe earlier. It must be based on assessment and it must be tailored to assist the child in individual areas of weakness. It would have to start as a pilot project or the cost would be enormous. The effect of a programme like this must be determined before anything large scale is attempted.

It is more likely to be successful if the basic problem is cultural than if it is constitutional. We know from the Headstart Programme that it would have to continue into the primary and secondary schools to be effective.

Finally, the family must be involved. It cannot be done by day nursery or by special programme. This also came clearly out of the Headstart Programme. The family must be interested and encourage the child to increase its motivation to learn. The history of people who have come up out of underprivileged areas shows that they often had a mother with a very strong drive for education. The home programme must continue throughout the day and this implies special staff working on it.

Now there are cultural problems in the Caribbean which may make it difficult to involve families. Education of children in the Caribbean may require changes that eventually need a special programme with a very wide basis.

Discussion

"The Pre-School Environment and Mental Retardation"

Chairman: **Miss Elizabeth Ramesar (Jamaica)**

Panel: **Mr. D.R.B. Grant (Jamaica)**
Dr. William A. Hawke (Canada)
Mrs. Juliet Robertson (Jamaica)
Dra. M. Sarasola (Dominican Republic)

Mr. Dudley R.B. Grant (Jamaica):

In our work with the Project for Early Childhood Education (P.E.C.E.) we have found from observation, and the little research that we have done, that parental interaction seems to have a very great part to play in the retardation of children of this age group. By parental interaction we mean the status of the parent, the occupational and the educational level. We are also thinking of the type of aspirations that the parents seem to have for the child. At present we are conducting parental interviews about the aspirations of the parents of children attending basic schools. We use the modified interview pattern from the Metropolitan Interviewing Scale. We have say ten children, and we ask the parents when the child leaves the basic school and goes to the primary school and he were to take a test, what position does the parent think the child would come in that test. Of the fifty parents interviewed so far not one parent has placed the child higher than seventh. In other words, they don't think that the child can come anywhere near the top. We are conducting similar tests with some middle class parents, and the reverse is the case, – 90% to 95% of the parents expect their children to come between first and second. Of course this is not conclusive.

So with respect to mental retardation and the parental influence on the cognitive development of the child, we have more or less found that the parents' influence could very well be divided into two areas – one the status, and the other the process of interaction. So we are thinking in terms of parental interaction.

Dra. Dora Sarasola (Dominican Republic):

We have been working for three years with the United Nations in the Mental Retardation programme. Tests are only a part of the things they use to know the abilities of the retarded children. Observation and other things are used because they think the tests are not the only things that could be used. By those means they discover not only the disabilities, but also the the abilities that the children possess.

They sometimes find out that deprivation of the environment makes the children act in a lesser way than what they can do. What Dr. Hawke said is similar to what is happening in Santo Domingo too.

Miss E. Ramesar (Jamaica):

I think Mr. Grant's point very interesting, because so far this morning we have covered the children's intellectual development. What we have not covered, and perhaps what is equally important, is their personality development. I think in other countries, particularly in the States, they have found that with poverty and cultural deprivation, the children tend to lack the need for achievement which they inherit from their parents or parent. They lack motivation, self esteem and have increased anxiety. This has not been investigated in Jamaica at all up to now and would be very interesting to find out.

Senora Garcia Cabrera (Puerto Rico):

I would like to ask Mr. Grant in your study you contemplate just the parental interaction. What about the brothers and sisters? We have had a similar experience in Puerto Rico and we have found that the interaction among the siblings has also something to do.

Mr. Grant:

We have considered the brothers and sisters, but at present we have run out of funds, so we decided that we had better concentrate on the parents, and trust to luck that this will convince the powers that be who provide us with funds to give us some money. What questions we have included for brothers and sisters, quite frankly are not enough for us to come to any definite conclusion.

Dr. Sally McGregor (Jamaica):

The majority of children in Dr. Hawke's survey were culturally deprived, poor and sub-nourished, even though they weren't so very mal-nourished. If we found a similar poor community in Canada, they might function very similarly. In the States the difference in pattern between the poor white and the poor black community may be very little. You cannot estimate cultural differences. Some tend to be slightly more creative etc. The problem here is really poverty, not Jamaican versus Canadian versus United Kingdom culture, but purely poverty.

Dr. W.A. Hawke (Canada):

I think we can answer the question about poverty because we are going to do a study on Indian people in a remote area of Ontario and they are certainly far from optimally nourished. They have very little money and the children come to school at the age of five speaking only Cree. We have to teach them English which is very interesting. The kindergarten is primarily an introduction to the English language. We are going to assess them, because we have a feeling from a very brief survey of some of the children of the second and third grades that they are doing quite well. They are bright and alert with reasonably facile thinking. We are going to see if our tests can be done by the children or whether they should be modified. We hope next year to have someone go and test the children using some of the standardized tests.

There is no question of poverty coming into this. We have people coming to Canada from the Southern part of Italy, who are undoubtedly from a poverty area, parents with very little education (most of them did not complete elementary education) and their children are doing well in school.

What I am coming to, is the basic relationship between male and female in family life in Jamaica. Where the parents are living together, and supporting each other; where the fathers are working and mother is looking after the child; these are the middle class families where the families do well because they are living for the next generation. These parents of whom there are only a few on the survey are willing to sacrifice themselves in order for their children to succeed. This has been true of many, many races. The big problem, of course, is the situation, where father is not available or is not married, where mother has to work, where grandmother is looking after a large number of children of different families. I think this accounts for much of the difficulties we are encountering with the children. And when we talk about family involvement, we have to realise that we are dealing with many of these underprivileged children in a culture where this is very difficult.

Really we are asking not only for pre-school education facilities, we are asking that many of the people of Jamaica to look at their way of life and their relationships to families.

Dr. Elaine Golding (U.S.A.):

Dr. Woo-Ming talked about the preconceived notions of the examiner and I do believe this is a very important issue in assessing children. One of the strong pressures that I have certainly felt in many of my colleagues who assess children are those exerted by the school system in not adhering to the self-fulfilling prophecies they want to make about so-called deprived children – black and Puerto Rican children particularly, in New York.

We need to reassess our values and attitudes. We talk about the motivation of the children. We should talk about our own motivations first and start accentuating positives in cultures of any sort, regardless of where they are, instead of talking about the negatives.

In Dr. Hawke's talk, he emphasized the gross motor tests. I feel this smells of the old business of what is to be expected of black people in terms of rhythm and action as opposed to language. I think that the West Indian language pattern is so intricate and different from outside that I am sure you could devise a test no Canadian, U.K. or U.S. person could comprehend and would put us in the high range of language development.

Dr. G. Woo-Ming:

I tend to agree with you because at the AAMD meeting the point was made that 83% of the black children in South Carolina are in special education classes, and this is one way to perpetuate some type of segregation legally. I disagreed with the idea of having only black psychologists test black children. There are good and bad psychologists, and in terms of the actual numbers you would actually be depriving the children if you tried to determine by race who should evaluate the children.

Professor John Figueroa (Jamaica):

I think that one of the things in the Jamaican situation which no one can face is the language business. This has nothing to do with genes. We founded a society with a creole language. What none of us can decide is: What language we really speak. It has created enormous difficulties. For instance it has been said that we don't use plurals. This is not right at all. The plural of "boy" is not "boys", but "dem buoy". We have to make up our minds which language we speak. This is a basic problem throughout the whole Caribbean.

I am not criticising the giving of tests in the manner in which you do, but we are not going into adapted tests. One of the problems of the developed areas is we need to develop tests of our own, but we don't seem to have either the desire or the monies to do so.

Dr. Leila Wynter (Jamaica):

I am pleased to hear that we have started something like this here and I look forward to the time when we are going to have our own tests, possibly in the language that the children understand and also using the various things in the environment that they understand.

Dr. W. Hawke:

I am not really suggesting the superiority of the Canadian over the Jamaican child. I was pointing out very clearly the difficulty of the test. I agree with Professor Figueroa. But it is perfectly true that if you score the Gesell as advised you can't give credit for the plurals that are used in Jamaica. We all agree that this is a terribly emotional subject. I know that when I talk about constitutional factors, immediately there is a strong emotional reaction. I am merely saying that the constitutional element must be considered. In time we may know how much is environmental and how much constitutional.

Dr. R. Fontaine (Venezuela):

The behaviour of a newly born reflects itself in the result of the weighing scale, probably that also has an implication in the development of their mental potential. I would like to know if you agree with that observation.

Dr. W. Hawke:

The question basically is a correlation between weight at the end of the first year and mental development, and I think our findings in the first year suggest that there was some correlation, if we remove the prematures and low birth weight children.

On the whole we did not see any children that we thought had true brain damage on our survey. There is good evidence that children with severe malnutrition – say Kwashiorkor – in the early years do not develop normally. There is undoubtedly a correlation between nutritional status and intellectual development, and the greater the degree of malnutrition, the greater the effect on development. However, I am not sure it has been proven that the earlier this develops, the greater the effect.

Mrs. Joan Coronel (Aruba):

How and where do you get the names of the children that are retarded? How do you find out who is retarded?

Mrs. J. Robertson (Jamaica):

The Project for Early Childhood Education does not deal with mentally retarded children, except for one or two who crop up in the basic schools which we supervise.
Mentally handicapped children come in various ways to the Jamaica Association. Sometimes teachers in primary or basic schools tell the parents. Doctors very often refer children and sometimes they come from the child guidance clinics. Parents bring their children directly in as well. These tend to be middle-class parents, and are increasing in number. There are parents who still refuse to acknowledge that their children are mentally handicapped, and there are a few who are still hidden away. Lower class parents either do not appreciate the problem or don't even know that facilities exist.

Mr. Cecil DeCaires (Barbados):

In 1963 we knew of six mentally retarded children in Barbados. We spent ten months using every possible avenue to find out the size of our problem. Those ten months produced one child, and so we very hopefully started our school catering for seven children. We now have 62 in the school and a waiting list of over 150.

I think you will find the best and surest way of finding the mentally retarded children in any community is to start a school, no matter how modest, and when people find out that there is somewhere that they can bring their children for help, they will bring them faster than you can cope.

Mrs. Pam Beaubrun (Jamaica):

I see mainly the children of poverty-stricken parents, who are very anxious when the child is not talking at two years or is not doing things like the other children in the yard. Sometimes the doctors think of referring them to me. But I will stress that the poorer parents are very anxious about their children living up to the standards of the other children in their homes.

Dr. A.C. Graham (Barbados):

We recently had a seminar on emotional disorders in children. The most important thing that came out of it, I think, was the fact that education and health were now meeting together to discuss a common problem.

Everybody agrees that the first five years are of utmost importance in the development of the child, one of the most important things that we must do to prevent behaviour disorders and emotional problems, to prevent deprived children, is parent education.

By parent education I mean a system whereby we can get parents to learn to communicate with their children. The importance of television in helping to develop language was mentioned.

If we can teach our parents to communicate with their children, not to ask too much of the child, be consistent in punishment and reward, this is the headstart that we need.

We have to find ways whereby we can do this with our limited resources.

Mrs. B. Williams (Jamaica):

In 27 of the 300 children that I saw at home over a period of three years, communication between the child and the child-minder or parent was limited to direct orders in 82.5% of cases. There was no genuine communication but just, "I want this so go and get it." Sixty-two point nine percent of the children did not possess or come into contact with a toy or book, and there was virtual absence of organised play or games in the home.

Dr. A.C. Graham:

That is very important. We stress rote teaching instead of the teaching of concepts.

Professor J. Figueroa:

What we need is a total re-thinking about what we are doing. It is said that our resources are limited. I don't think that of the gross national product we spend in Jamaica more than 3% or 4% on education. That is not good enough, especially when we follow the tradition of not spending it on the first five years. This is a world-wide phenomenon and we should ask ourselves (this is where the parents and the rest of the community come in) if we do have limited resources, where do we put the money? This is of course a political and socio-economic problem.

Mrs. Robertson:

I agree with Dr. Graham and Professor Figueroa about rote learning in the early years. The Project for Early Childhood Education is experimenting with getting the teachers to use the play approach from ages 4 - 6. Early findings indicate that when these children go in to a normal primary school, they do tend to achieve more than the children who have been through the rote learning.

This research has not been completed, but results do seem to show that this kind of education at the beginning of the school year does produce a child who is ready to learn and is better able to form concepts later on.

Dr. W.A. Hawke:

There is another question which I think has not been answered. We develop certain skills at certain times and if we don't achieve them by a given age, we would be unlikely to develop normal skills.

Can we take a child of six and give him a programme which will enable him to function essentially well in school, or do we have to begin at the age two? I suspect that you have to begin at an early stage, and that giving two or three times the programme at six, seven or eight will never achieve the level if you had got them at the vital stage of their development.

Professor E. Back (Jamaica):

This project which Dr. Hawke has been talking about started nearly four years ago, the object being to find out what in fact does happen. These children were not chosen because they were culturally deprived, they were taken off the production line in the University Hospital in 1967. There are three hundred of them all together.

Professor Figueroa has said the language which is spoken in the homes of Jamaica is not the English spoken in the schools. This may be one of the reasons why they do so badly in school. We know when we see them in baby clinics at the age of one year, that they will pass for good children anywhere. Somewhere in between they are falling back and we wanted to find out first of all when, and then also perhaps why a large number of these normal babies end up at the age of eleven as mentally retarded.

This vast mass of preventable retardation does seem to be well worth our spending our limited resources on.

Dr. Graham:

In Barbados we spend more on education than on health, or any other group. I think that this might be one of the reasons why we have got a 97% literacy rate.

We have got at least one government sponsored project of nursery education. We try to take as underprivileged a group as possible. We have teachers from Erdiston College going across to Erdiston Nursery School and being exposed to this type of education.

Senora Garcia Cabrera:

I would like you to define a concept. I am worried about the definition of parental interaction. I would like to know what criteria you use for your measurement – to test the measurement. How do you know the quality and quantity of parental interaction?

Dr. W.A. Hawke:

I suspect that very often it is really on the questionaire basis. Someone has a psychological questionaire which is standardized once again on another population and that is given in as clear a way as possible to a new population.

I may say that if you think you have your problems, we are in the middle of a tremendous educational upheaval at home. They want greater freedom, more interest, less structure, less discipline, each child to progress at his own rate, and optimal development including fantasy, etc. You have your problems here; we have problems at another level that are tremendously confusing.

Professor J. Figueroa:

I think I can say this of Jamaicans that without any cruelty at all, "Children are to be seen and not heard". Many parents don't realise that unless you speak to children about things that they understand, they will never come to understand.

I think there is a real problem here, which Dr. Hawke and Mrs. Williams are trying to look at, namely what is the relationship of the speech behaviour of the environment to the language development. Taking an educated guess, I would say there is a problem that we don't involve our children in meaningful speech activities. We involve them in the rote business.

Dr. W.A. Hawke:

Some of the families where one has a grandmother with four or five or six children, I would suspect that if they were talkative and active and energetic she would be completely unable to control them.

But I think this is a cultural thing, really. We have to realize that it is probably the only way that these families can function is by having this degree of control over their children.

The other thing that interests me, and this is a little bit more obviously half-baked, is the basic way in which the boys are treated in the culture. The daughter is impregnated by someone who says, "So nice to have met you, goodbye". Or she marries the chap. The male child meets the hidden hostility of the grandmother to the male of the species. One of the ways of child rearing is to keep the male down and to control him that he may suffer for his father, or at least he obviously is not going to do as his father did. This is not original thought.

Mr. A. Voorhoeve (Jamaica):

I have completed a study on intelligence in Jamaica using a small number of children obviously, so we can't generalize from this too much, but what I found was that there was no difference between boys and girls. There was a fantastic difference however between rural boys and girls, and city boys and girls, as much as 1½ standard deviation difference. We use a somewhat modified Wechsler Intelligence Scale for children, with questionaire and so on. We found that there was a good distribution, in other words that the test is sensitive to picking up people who are very low and very high. That does not in itself make the test useful, anyway it indicates that it is measuring something, whatever that may be.

Also I had a nurse going round asking parents what their children did, the kind of things they liked, the kind of books they read and so on, and I found that there was a very high correlation when there was agreement between these questions, between the child and the parents, in intelligence.

In other words, if you asked the child what he wanted to be and he said a pilot, and the mother says yes he wants to be a pilot, then the intelligence was high – relatively high. If the child said I want to be a truck driver, and the mother said she wanted him to be something else, but there was no agreement, then there was no correlation. And I think that the verbal contact, the communication between parents and children is very important.

But again we don't know which comes first, the communication which makes the child intelligent or the parents are intelligent anyway and therefore they communicate.

I think the test is good for predicting how well a child will do in school, in the future. I correlated this again, the marks that the children had in school and the assessment of the teacher. Another thing I did was to ask the teacher to give me their brightest child. The I.Q. was always higher than 100, as high as 110 and 112. So when we test somebody with this test and they get a high score, well we can say that this child will do well in school. If they get a low score, we probably say that they will not do well in school.

I was testing children from eight years, I could not get children under this because many parents don't send their children to school before they are eight years of age. I found that at all ages they were behind, and that there was no widening.

. Dra. D. Sarasola:

Each one of us should go back to our countries and try to get the government officials interested in educating the children before three years of age. To prepare technical persons to attend the education of the mentally retarded population, these technical officers should be university level education. We will have to speak for the retarded. Some people think this money is going to be lost. There should be mass education to encourage the programme and defend the mentally retarded.

Dr. W.A. Hawke:

Would the audience agree to a pilot project, because it has to be pilot, of the type involving many departments looking at the family involved? This is something that should be suggested.

I want to stress family involvement because it has come out so clearly. The point is that many people do not like people like myself from Canada coming in and saying, "This is the way you must raise your children." It is much better if the people themselves carry out the educational programme, and it is much better for you to involve the parents in the programme than having a professional even from the Caribbean do it. This is vital.

Mr. A. Voorhoeve:

I should like to make one comment that obviously for any project one sets up, funds are needed, that there is a correlation between birth-rate and setting up a programme of early childhood education. If once there is a programme for early childhood education in an area and parents get the message that their children will have a chance to succeed in life, then obviously the achievement motivation of the parents for the child will go up, that they also realize that they cannot bring up fifty children to become a doctor or a lawyer or whatever their aspirations are.

Mr. Francis White (U.S.A.):

We must face up to the problem of mental retardation with the simplest approach that we can get the greatest benefit. I think one of the greatest needs is to make the public aware of what mental retardation is, and make them also aware that the retarded can be helped – and when I say the public this applies to the government too. We can't go to the government to ask for financial assistance unless they feel that their constituents are aware of this and want it and demand it also.

We have to also educate the general public and the parents, and I think in accomplishing this a strong parent movement in each locality is very vital in the accomplishment of doing this basic selling job.

Mr. A. Voorhoeve:

There is no Department of Psychology at the University of the West Indies. At the moment, the only people who are taught psychology are some in the Department of Education, Sociology and in Medicine. There is no specific course leading to any kind of degree in psychology. So I recommend that we set up a Department of Psychology at this University, at this campus or the other campuses, or at least courses be given in child development if no department can be set up immediately.

Professor J. Figueroa:

Although this is a conference on retardation I hope you will link this with some sort of regular formal education with this age. I think it would be a pity if all that we have said this morning should sound as if we are only thinking that those people who are mentally retarded need the stimulation from age two. We must ask the community to make a commitment to itself and to its children, and therefore to be willing to spend money on the education of its children, and at this level.

RECOMMENDATIONS

1. There is a need for early institution of pre-school education with emphasis on teaching by conceptual method rather than learning by rote.

2. There is also a need for parent education in child development and stimulation for the normal child.

3. There is a need for better preventive services, ante-natal care, early diagnosis and genetic counselling.

4. Need for courses in child development and psychology in the University of the West Indies.

5. Research into the effects of the West Indian cultural environment in producing mental retardation.

SESSION II

The School Period

Plenary Session: Topic 3

"The Training of Teachers for Mentally Retarded Children at the College of Education of the University of Puerto Rico."

by

Professor Delia E. Lugo

University of Puerto Rico

September 7, 1970.

Introduction

The education of mentally retarded children, as that of other handicapped children, has always been a problem for the public schools since it requires alterations in the curriculum and the teaching methods, additional facilities and equipment, and, most of all, adequately trained teachers which are not always available.

When these conditions cannot be met by the school system, the mentally retarded child has to depend upon private institutions for his education or has to compete with his more advantaged peers in a regular classroom even though he is not equipped with the necessary capacities for this competition.

Some of the less retarded children, helped by good teachers and cooperative parents, are able to "survive" in the regular classroom, that is, are able to reach a minimum achievement that allows them to work out a position in society. But many others, especially the more severe cases, or those with the poorest home environment, have to drop out from school or simply never attend. This fact has definitely contributed to the aggravation of social problems such as delinquency, drug addiction and unemployment.

We do have some evidence for this. For example, a study made by the Council of Higher Education of Puerto Rico[1] has shown that school drop outs had very low achievement in school and great dissatisfaction with school demands.

Another study made by the Department of Social Services of Puerto Rico[2] showed that 60% of the interns of the institutions for juvenile delinquents were mentally retarded.

However, as the school system begins to ameliorate or solve some of its basic problems it starts to open opportunities for the retarded child and other exceptional children. This has been the case in Puerto Rico.

The Special Education Programme for Mentally Retarded Children of the Department of Instruction of Puerto Rico.

According to the last census (1970) Puerto Rico has a population of 2,700,000 inhabitants. Estimating the prevalence of mental retardation on a basis of 3%, there are about 81,000 mentally retarded persons in Puerto Rico.

There are several public and private institutions that take care of the most severe cases of mental retardation, but most of the educable mentally retarded children attend regular classes in the public schools.

During the last twelve years, the Department of Instruction has organized and carried on a special education programme for mentally retarded children. The first group was organized in 1958 as a pilot programme. It consisted of 18 educable mentally retarded children. Even though the teacher had not been trained in special education, the results obtained were so encouraging that the Department of Instruction decided to expand the Programme. At present there are 300 special classes of handicapped children being most of them of mentally retarded children both educable and trainable.

The need for special education in Puerto Rico is so big that the Department of Instruction intends to organize more special groups at a rate of 40 per year.

The Special Education Teacher Training Programme at the University of Puerto Rico.

One of the greatest difficulties that the Department of Instruction has encountered in the implementation of a special education programme for mentally retarded children has been the lack of trained personnel to offer this type of education. The College of Education of the University of Puerto Rico, conscious of this need, made up a proposal to the Office of Health, Education and Welfare of Washington applying for funds to establish a programme for the training of teachers for mentally retarded children. Backed by Public Law 85-926, as amended, the proposal was approved in 1964 and a grant of $20,000 was received for this purpose. The Programme was organized during the year 1964-1965 and started to train the first teachers in 1965-1966. It has been functioning, on Federal funds, for six years now.

During these six years (the first year was dedicated to the organization of the Programme) about 165 teachers have been trained to work with mentally retarded children. Many more students have taken courses of the Programme as electives.

The Programme offers six fellowships to junior students consisting of $300 a year and ten fellowships to senior students consisting of $800 a year in addition to the payment of registration fees. The University receives $2,000 per student registered in the Programme.

Every year the Department of Instruction gives leave of absence to about 20 teachers working with mentally retarded children to come to the Programme to be trained in special education.

At present the Programme consists of 8 courses plus Practicum for a total of 29 credits. The courses offered are:

Ed. 341–Introduction to the education of exceptional children
Ed. 313–Psychology of mentally retarded children
Ed. 314–Curriculum and methods for educable M. R. children
Ed. 326–Curriculum and methods for trainable M. R. children
Ed. 399–Diagnosis and remediation of learning disabilities
Ed. 335–Psychology of emotionally disturbed children
Ed. 301–The child and his social environment
Ind. Ed. 201–Arts and Crafts for mentally retarded children

All students in the programme are required to practice teach four hours a day for a whole semester. Practice teaching is done at the special classes for mentally retarded children that the Department of Instruction has established in the public schools near the University campus. Practice teaching is supervised by the professors of the Programme.

Two new courses in special education have been added to the Programme this year:

Ed. 353–Education of the visually handicapped
Ed. 361–Education of emotionally disturbed children

Two other courses were offered during the summer:

Education of children with speech problems
Education of children with hearing problems

Besides teaching in the regular teacher training programme, the staff co-operated with the Department of Instruction in the in-service training of teachers working with mentally retarded children through the island. The staff also does consultation work for private institutions for mentally retarded children.

Projections

Up to now the programme has trained teachers to work specifically with mentally retarded children. The students that complete the Programme get a minor in mental retardation. However, since the Department of Instruction has been

organizing special education classes for other types of exceptional children, the Programme is offering courses in other areas of exceptionality. It is now being proposed that the Programme offer a major in special education including courses in all areas of exceptionality and minor in a specific area such as mental retardation, emotional disturbance, visual handicap, etc. This would prepare teachers to work with mentally retarded children that are multiple handicapped which seems to be the real need of the Department of Instruction at this moment.

On the other side, the Programme has been functioning on Federal funds up to now. It is expected that it will be absorbed by the University and become a permanent one at the College of Education in the near future.

Plans are also being made to offer a special education programme at the graduate level.

REFERENCES

1. Consejo Superior de Ensenanza, Universidad de Puerto Rico, Rio Piedras, P. R., **La Desercion Escolar en P. R.**, 1964, 190 p.

2. Information reported at **Helping Them Help Themselves**, a report to the Legislature made by the Office of Mental Retardation, Department of Health, Santurce, P. R., June 1966, p. 8.

Discussion

"The Training of Teachers for the Mentally Retarded in the Caribbean"

Chairman: Mr. Francis Hardy (U.S.A.)

Reactor: Mrs. Nesta Patrick (Trinidad)

Mrs. Patrick:

In 1961 Lady HoChoy Home started and my school at St. Ann's Hospital has been going for 15 years.

I felt that primary school teachers needed to have some insight into problems related to learning. I borrowed money from the P.M. to pay for the first course. This was for 36 trained teachers with 10 years experience. They had a 2 week residential course. This involved Ministries of Health, Education and Home Affairs. Then a training course for principals was started in which they nominated their best teachers for the course. Four courses have been given and so far 144 teachers have done it. But there are 456 primary schools and each school must have at least one teacher trained. I direct the course and the senior education officer is Chairman.

The first day deals with the review and each teacher contributes. We do intellectual development, testing and diagnostic techniques. The lecturers are people who are convinced that this field is important. There are also lectures on personality and behaviour, social development, practical teaching (teachers must go back with the curriculum) mental retardation (at psychological and practical levels) case studies, physical defects. We improvise our own testing system. We also do physical education for the handicapped child, arts and crafts and show films.

Later they do evaluation exercises, and get a certificate. They also do essays. They later take over a special class in their primary school. The schools then have to be visited, which I do. Problems are discussed and referrals to clinics made. The course is run every April. The ministry sends out information to all the schools from time to time.

This is only scratching the surface but we feel that it does give some help.

Mr. Francis Hardy:

In our particular university we have two programmes. The undergraduate programme in which the student is an enrolled member of the university. All of our teachers, regardless of when they become special teachers must have elementary school teacher training first, or along with it. They are certified when they graduate to teach either elementary, normal grades or special education. But not all elementary school teachers are certified for special education. They take a special course and they get a dual certification. That's the undergraduate level.

On the graduate level, we have a course for those who are now employed as teachers, and perhaps some other discipline, but who express an interest and a desire to go into special education. They then do their graduate work in mental retardation or physically handicapped, or speech problems, and get their further degree then in special education. And then they are certified as special teachers.

Professor Lugo (Puerto Rico):

We only have one teacher training programme at the University of Puerto Rico. They offer one course at other universities, but not a programme like that. Our teachers get the training as normal teachers – as teachers for normal children first. Then at the last year they get the special training in special education.

Dra. Sarasola

They train teachers in two years at a graduate level. We also offer this training programme as a resource, but it has to be for Spanish speaking teachers. We are training 61 teachers now.

Miss C. Hanna (Bahamas):

I want to know if the Trinidad programme is endorsed or certified by your university, or your training college. Do the teachers get any personal emoluments for doing this course? What sort of recognition is given by your Department of Education for this short course?

Mrs. Patrick:

The training course is recognized firstly by the Ministry of Education. We hope next year that the University of the West Indies will take the course completely away from us and do it effectively. That is number two. Thirdly, they are recognized in that I told you they have ten years teaching experience. They were chosen by the headmasters. When they returned duly qualified with their certificate from the Ministry of Education, Ministry of Health and Ministry of Home Affairs they are given an increment and they have the special responsibility of dealing with this class in their schools.

Dr. Woo-Ming (Guyana):

Most of the schools that we have heard about so far, the voluntary schools, seem to have the children who are just trainable or below. Do any of the three programmes actually train teachers for working with moderately and severely handicapped children?

Mr. Hardy:

Our programme trains teachers for practically every area of exceptionality. The one in Puerto Rico too.

Professor Lugo:

They can choose to do their practice teaching with trainable or educable – whatever they want to do, but we train in both levels.

Dr. Thorburn (Jamaica):

In Jamaica we have absolutely no training scheme for teachers. Until this year we had no trained teachers in mental retardation at all. We now are very fortunate and have got two people who are fully trained – one from the United Kingdom and one from the United States.

The reason we have been able to get two fully trained people from abroad is because the Ministry of Education has now recognized our school as a Special school. They would not recognize it until we had fully trained teachers and we could not pay fully trained teachers until the school was recognized. This is a big break through, and makes a lot of difference to us.

We have some plans. We are hoping that Mr. Hardy who, knows Jamaica very well and has taught here in the past for three years, will come and conduct a summer vacation training course that would last for about six weeks.

Now, unless a training college or the university, agrees to take on a mental retardation training programme, and this is going to take some time to implement, we have to try and look for some sort of interim solution. This morning we were discussing in the Assessment Session ways and means of getting over the lack of psychologists. Now we have to discuss the ways and means of stopping the gaps before we can get fully trained graduate teachers in mental retardation.

The teachers that we have been using have been primary school teachers, and those trained on the Project for Early Childhood Education. The latter have been very helpful. Before we can get fully qualified people should we not use people who have this training already, and try and conduct some sort of in-training course during the year, under the supervision of a well-qualified instructor. Maybe through regional collaboration we could get a proper training course.

We would look towards one of the teacher training colleges offering a specific course in mental retardation which would take place after their normal teacher training course is finished.

Mr. Hardy:

This is being done in many places right now. In the United States for instance, many of the associations for retarded children have teachers who are not qualified as such, but are very fine workers with the children, and have had years of experience.

Recognizing this fact, seminars and workshops are now being conducted on week-ends and so forth over a period of time to try and bring professional help to these people.

Dr. Williams (Guyana):

Does the Faculty of Education of the University of the West Indies offer a Diploma course to qualified teachers? Has there been any thought given to introducing a specialized course for at least the ESNs in your course? I ask that because one of the things that struck me only since I got here was that in Guyana there is a Diploma Course attached to the University of Guyana for teachers who are already teaching in the Primary Schools, and I was wondering whether we could not try to involve them in running a specialized course at least for ESNs if not at the beginning, for the more retarded children.

Mrs. Sheilah Gibson (Jamaica):

I work for the Institute of Education here and my job is to go around the Northern Caribbean, and I am very heavily involved with teacher training as well as work on the campus here.

There is always a very great demand from teachers all the way round for help with this programme. When I first came out here in 1966 Child Development was not included in the teacher training programme. Now I am happy to say it is. This obviously has to be the basic start. Church Teachers' College in Mandeville now does a course on ESN on backwardness in schools, so that is one place that is starting. Individual students doing the Diploma can follow this up, but it is not our general course. Things are improving, but there is very heavy demand for help with this subject.

Dr. G. Allan Roeher (Canada):

We have had a similar experience in respect to pre-school programming, and I should just like to mention the strategem that has worked for us. Again it was on the point of Child Development – basic background in child development. We had some 90 people who worked in pre-school programmes in Ontario. These were people who were just recruited by the Association.

Help came from the Department of Social Welfare because Education was not ready to recognise pre-school programmes as yet. Their point was that there must be some level of certification for them to give support to these programmes.

The plan that was worked out was a correspondence course in child development, which was conducted from the University, but was sponsored by the Association in co-operation with the Department of Social Welfare. There were 85 people. They were not really teachers necessarily, who joined up for this course and they came in for the next three or four days of fairly intensive work early in September. Then they were given a series of correspondence lessons that were sent out every three weeks, over a period of some seven months, then brought back for another 3 – 5 day intensive session and then they had to spend two weeks in a normal day care programme. At the end term the instructor of the teachers visited them in the regional grouping setting in order to relate what experiences and problems they had. It was highly successful and we are now expanding on a national scale. This is one way of reaching people on an interim basis. Now, whether or not this principle can work in situations where it is a case of getting started, I don't know.

Miss Elizabeth Ramesar (Jamaica):

I am a psychologist of sorts, but I work as a Guidance Officer for the Ministry of Education here.

The Child Guidance Office at the Ministry is trying to go into the Teacher Training Colleges to either volunteer to give courses to teachers on Child Development or to try and fit in some way in an already existing programme.

We have two Peace Corps Volunteers working from our office in the Kingston and St. Andrew area, and they will be working with the colleges at least one day a week for the next year. Un-

fortunately, they will be leaving Jamaica after a year, but we have already written letters to the training colleges, and as soon as session starts we hope to be offering these services.

Dra. Sarasola:

She thinks that from the diversity of language spoken in the Caribbean, two pilot programmes should be established – one in English and one in Spanish. She says that she has been authorised by the Dominican Government to offer a Fellowship for Spanish speaking people to go and get the training for a two-year period. She also suggests that other programmes like the ones that have been mentioned here – Canada and Puerto Rico – be used as pilot programmes to start training teachers that are English speaking.

Dr. Graham (Barbados):

I think it very important that the University of the West Indies and the Institute of Education is the body to do these courses because of the smaller islands in the Caribbean.

You have in the various island branches of the Institute in the same way as you have the Department of Paediatrics moving throughout the Caribbean.

Dr. Williams:

I really think that we will have wasted our time at this conference if we don't develop a regional approach to this whole subject.

Dra. Fontaine (Venezuela):

They have had ten years experience in teacher training and they have had great difficulty in the selection of candidates for training. He wants to suggest that you give some kind of an introductory course where the teacher can find out if he really likes it and has the appropriate attitude to the teaching before you start the teacher training programme, unless you have already selected your candidates.

Mr. Hardy:

This is very true and in our particular situation the candidates have quite a bit of familiarisation with the children before they definitely decide that this is the course that they want to take.

This could be done by radio and television. When I was first in Jamaica I did music teaching to the country schools by way of radio, so I know that it can be done.

Mr. V. Serritella (Jamaica):

I am with an association in aid of the deaf which does have a training course as such for teachers of the deaf. I think it is relevant to the situation here today from a Jamaican context. In years past the association did have trouble in picking the right kind of candidates. There was about a 50% drop-out rate of all teachers coming back from the United Kingdom or teacher training colleges to the setting to teach. They learn the pure form of deaf education in the United Kingdom or Canada and come back to the realities. We have had much more success with teachers actually teaching within our schools for a one or two year period, working with a trained teacher of the deaf day to day that is, and then going away after this for a one or two year period for training.

I should also like to add for your information that within the next year the Institute of Education at the University of the West Indies will be sponsoring a teacher training course for teachers of the deaf.

Dr. Thorburn:

I am sure everyone else in the Caribbean has had the experience of people going away to train from the very beginning in a different environment, that either they don't come back, or if they do they are very dissatisfied because they can't apply what they have learned.

I feel very strongly that any type of training programme has to be done in the Caribbean. We may bring outside people in to help us, but they also must have knowledge of the Caribbean and its culture and so on.

The other point is about selection of teachers. One way that selection may be made is, that if you have a school already, to invite training colleges to send groups of students for a day to see how the school operates and see that children who are retarded are not quite as fearsome as they imagine. Show them a couple of films of what can be done in other countries possibly. After that you can offer a course, I suppose you will still get drop-outs, but a least you may have a better success rate

Mr. Serritella:

I think one of the biggest problems in any kind of teacher training programme is recruitment, and realistic recruitment. In discussing any kind of teacher training programme, recruitment should get as much attention as the actual training of teachers.

Dra. Sarasola:

She does not think a teacher can be trained in two weeks. She said this needs a lot of time in clinical experience, so she is kind of worried that the training would be done too superficially.

Mr. Hardy:

I believe all of us would agree with this, but we have to sometimes do the expedient thing and then hope that we can do further after that. In Aruba where they have four schools for mentally retarded in a population of 60,000, their training programme is two years and nine months.

RECOMMENDATIONS

1. A survey by a central co-ordinating body of the training resources should be made. At present Universities of Puerto Rico and Santo Domingo offer graduate courses. Trinidad offers a two week course. Jamaica has no training scheme. Venezuela has a teacher training scheme.

2. There should be two types of courses available, a two year training course and a nine months course. Santo Domingo feels that no less than two years is satisfactory.

3. An approach should be made to the University of the West Indies to have a graduate teacher training course offered in the curriculum.

4. Approaches should be made to teacher training colleges to have them offer a six months course in mental retardation which would follow the normal two year course.

5. There should be a combined approach to a summer school training programme.

6 There should be people to move around the smaller islands and perhaps conduct short courses.

7. Training should be in the Caribbean. Personnel sent away to train either do not come back, or if they do, they find

their work situation is so different from the atmosphere of their training that they are dissatisfied.

8. There should be an interim in-training scheme in the present schools for retarded children to fill the present serious gap.

9. To establish two pilot centres for teacher training in mental retardation in the Caribbean, one Spanish and the other English. Each country should create fellowships for this purpose and should select its own candidates.

SESSION II

The School Period

Plenary Session: Topic 4

"Alternatives to Public Institutional Care"

by

E. L. Johnstone

Consultant,
President's Committee on Mental Retardation,
United States of America.

September 7, 1970

In making a case for alternatives to public institutional care of the mentally retarded, it may be well to inquire just why it is appropriate to do this. For countless years, the public institution has been the principal – often the only – resource available to those retarded who cannot be cared for in their natural homes.

Public institutions, as most of us know them, have certain similarities. They are large in size and are multi-purpose in function. They represent the unfortunate inheritance of an archaic philosophy of care and total provision for those whom they purportedly serve.

One compelling reason for the current search for other programmes, techniques and resources, is the recognition that the vast majority of publically operated, congregate institutions are woefully inadequate from any point of view.

This has been documented in a book issued by the President's Committee on Mental Retardation in 1969 and entitled "Changing Patterns in Residential Services for the Mentally Retarded." Primarily, it applies to existing residential services in the United States.

It illustrates just how a country can get so locked-in by tradition, that embarking on new, innovative programmes becomes a colossal undertaking. It further illustrates the enormous difficulties encountered when men of good will undertake to break with the past in order to plan for the future.

In the first chapter Dr. Robert B. Kugel says:

"Unfortunately, there is little good news when writing about residential facilities in the United States, although considerable and even outstanding progress is being made in some areas of mental retardation. Among these are the growth of day centers for severely handicapped individuals and of employment opportunities for retarded and handicapped individuals in general. Throughout the country, programmes in public education have helped to dispel some of the darkness of the past. Research . . . biological, sociological, and behavioural . . . is a hallmark of the American scene. Volunteer efforts for both the retarded and physically handicapped have been outstanding. Innovations in behaviour shaping are pointing the way for better management. Diagnostic services for the retarded also have been among the outstanding successes.

Why, then, have residential facilities lagged so far behind these other areas in which advancement has been considerable?"

Bengt Nirge, of the Swedish Association for Retarded Children declares:

"In the last two years, I have visited a number of public institutions in several states, and on each occasion I have reacted with disbelief and bewilderment to what I saw. I found it difficult to understand how a society which is built on such noble principles, and which has the resources to make these principles a reality, can and will tolerate the dehumanization of a large number of its citizens in a fashion somewhat remindful of Nazi concentration camps."

The eminent Dr. Jack Tizard writes:

"The usual type of residential care for the mentally retarded in the United States, as well as in most of the rest of the world in which services have been provided, is the large comprehensive hospital, training school or institution which contains both adults and children at all levels of retardation. In the past, justification for the large size and heterogeneity of population was mainly economy. Large institutions were believed to be cheaper to run than smaller ones, and in institutions containing mildly and severely handicapped residents, the less handicapped were able to contribute very substantially to the care of the more handicapped and to the general running of the institution."

Dr. Lloyd M. Dunn comments:

"1. It is my contention that a century of failure of the large, multi-purpose residential facilities for the retarded (as we know them) is enough; we need now to test the effectiveness of other procedures.

2. Further, it is my belief that we have the knowledge and ability to design and research these alternatives.

3. Still further, it is my hope that the efficacy of small **special-purpose** facilities will be examined as one of these alternatives."

Dr. Karl Grunewald contributes this:

"To us, in Sweden, the advantages of the small residences are so clear that it is generally accepted that everything must be done to enable the majority of the mentally retarded to be cared for in such residences."

Finally, Dr. David Norris says:

"In the last twenty years, we have witnessed in Britain a growing interest in the conditions which surround the mentally handicapped and their families. Mounting awareness of the poor quality of provision for the mentally retarded led to the development of a climate of opinion in which it became possible to plan for the needed services. Up to this time, most of the provision for the mentally handicapped was made available by the institutions, and public expression of private discontent naturally surrounded these institutions which had to deal with the bulk of this problem. As a result, many people have been vigorously pressing for the establishment of hostels in which the mentally subnormal can be cared for under better conditions than those associated with the large institutions."

In the face of such overwhelming condemnation of the traditional institutions as the principal agency for services to the mentally retarded, there is ample reason to understand why there is, presently, great clamor to provide alternative methods of care.

I am not suggesting that all existing institutions be abandoned and razed to the ground. In all probability there will always be a need for public residential facilities offering specific rather than general services. The severely and profoundly retarded and those with multiple handicapped conditions who require highly specialized programmes may be cited as examples. What must be avoided is the creation and the perpetuation of what have frequently been referred to as "warehouses for human beings".

Let me also make it very plain that in repeating the harshly critical quotations above, it is not my purpose to castigate the individual superintendents who are responsible for running these institutions. With few exceptions, these men and women are well qualified and well intended. More often than not, they are doing heroic work in the face of many obstacles. Their institutions are usually under-staffed and over-populated. Salaries and wages, in the main, are inferior to those in private industry. Physical plants and equipment are generally old and functionally inadequate for the task at hand.

With respect to the age of public institutions in the United States, the first report of the President's Committee on Mental Retardation submitted in 1967 pointed out: "Three-quarters of the nation's 201,000 institutionalized mentally retarded live in buildings fifty years old or more – many of them 'hand-me-

down" mental or tuberculosis hospitals or abandoned military installations.

The tragic fact remains that many states, in erecting new physical facilities continue to build large buildings, following the same old dreary patterns of the past. Thus the forward-looking, aggressive superintendent finds himself a victim of the "system" which compounds his frustrations.

If there is a question in the mind of any of you as to my own right to speak with familiarity and authority on the subject of public institutional services for the mentally retarded, let me set the record straight. For nearly twenty-five years I served as superintendent of such an institution in the State of New Jersey. This institution conducted a specialized programme in that it provided for severely and profoundly retarded males. During my tenure from 1929 to 1953, the population increased from about 350 to over 1,000. The philosophy changed from one of minimal custodial care to one of training and rehabilitation within the limits of the inherent capacities of the individual resident. We knew nothing of "operant conditioning" or "behaviour shaping" as those labels are applied today, but we practiced it just the same.

Also, in recent years, I participated in the programme of evaluations of public residential institutions in the United States, which project was conducted by the Division of Special Studies of the American Association on Mental Deficiency. During these tours of duty, my assignments included evaluating about twenty such facilities ranging from the newest and the best to prototypes of the oldest and the worst. And in the course of my professional career in residential administration, I have had the opportunity to make one or more visits to some fifty-five public institutions in the States and countless private facilities both at home and abroad.

To return to what Dr. Tizzard said about economy being a justification for large size and heterogenous population of an institution. To my mind, this is a myth.

The superintendent of the Gracewood, Georgia, State Hospital and Training School, Dr. Norman C. Pursley last May spoke of costs at his institution. His predicted budget needs for fiscal year 1972 indicated an annual average cost per resident of $7,500. In 1951, the actual annual per capita expenditure was $551. In 1961, ten years later, it had risen to $1,670. In fiscal year 1969, the figure was $4,873.

According to Dr. Pursley, another 1,000 bed institution with a programme of heavy emphasis on manpower training and research anticipates that ". . . the annual per capita will be $14,600 or about $40 per day". These figures are for the operating budget only and do not include land costs, costs of construction and the like. This is little short of shocking and it leads me to two conclusions. First, the taxpayer is going to start taking a questioning look at such expenditures. Second, I am convinced that private enterprise and competition can do a better job for less money.

In the preparation of this paper, I have tried to keep in mind that one of the goals of this Conference is to set in motion mechanisms and actions which will have realistic application to future provision for the mentally retarded in the Caribbean area. The emphasis on deficits in public institution operations is not merely to extend criticism. It is, rather, to indicate that, by avoiding mistakes of the past, by breaking from tradition, a brilliant new and innovative approach may follow in establishing services for the retarded in this area.

What are alternatives to public institutional care? A great many are known and are presently being utilized, albeit on a relatively limited basis. Dr. Kugel touched on certain of these when he referred to day care centres, employment opportunities, results of sociological and behaviourial research, and the like. Other authors who contributed to "Changing Patterns" documented specific alternatives as well as recommendations and suggestions for drastic alterations in methods employed by residential facilities themselves.

These would include:

1. Subsidies to families to encourage care in the natural home of the individual.
2. Foster home placement.
3. Special classes in the public school for mildly and moderately retarded.
4. Sheltered workshops.
5. Programmes for vocational training and rehabilitation.
6. Day care facilities under both public and private auspices
7. Short-term treatment and training centres.
8. Group homes, or hostels, for the more mature and potentially employable.
9. Nursing homes for older retardates who have passed the point where they will profit by regimens of training, education and social rehabilitation.
10. Residential facilities operated by private enterprise, both proprietary and non-profit.

Other alternatives will undoubtedly emerge as our knowledge and sophistication grow.

The problem, as I see it, lies in ascertaining where, how and under what sets of circumstances and local conditions, any one or any combination of these alternatives can be applied. The nature of the individual community, its social and cultural mores and resources will bear heavily on finding the answers.

Yet, find answers we must. That is the essence of this Conference, and, as I look at all of you dedicated and sincere persons gathered here, I am encouraged. It is my strong conviction that as result of these meetings, and the exchange of ideas and knowledge, you will return to your homes and your communities with new courage, new inspiration and new determination, to meet the challenge of providing effective and humane services to your retarded brethren.

In conclusion, I offer this thought: For too long, we have regarded the mentally retarded in terms of their liabilities, their deficits and what is **wrong** about them. It is high time we view them in terms of their assets, their potential capabilities and what is **right** about them. Remember, the retarded are not a separate race, or breed, or culture. The difference between them, and between us is a difference in degree – not in kind!

Discussion

"Alternatives to Institutional Care"

Chairman: **Mrs. Beverley Marsh (Jamaica)**
Reactor: **Sister Gemma Camacho (Trinidad)**

Sister Gemma:
I would like to tell you something about how our home in

Trinidad is ru-.

In March 1961 we made a break with the past with a special type of residential home which also houses a day centre on the same compound, geared completely to training and rehabilitating, but developing to its utmost, the human potential of the individual. The institution has a capacity for 200 residents and 100 day pupils. We constantly face the risk of over-crowding and there is a long waiting list. We have just started another centre in the south of Trinidad and at the moment this accommodates 60 day pupils. These residential and day centres are sponsored by the Association for the Retarded in Trinidad, and subsidized by Government with management by the Carmelite Sisters.

We feel that we should now have nursing homes for our older retarded. They cannot benefit from the training the younger ones are having. The older ones, some of whom are untrainable, mixing with the other ones who are trainable, we don't think that this is going to help them.

We would like to concentrate, for the future on making the retarded more productive. However, all programmes must emphasize the dignity and worth of the individual.

We also carry on a special programme at the home for brain injured children. Simple forms of exercises are done at intervals throughout the day, six hours for six days a week – a very intensive r gramme. Exercises – creeping and crawling – we feel stimulate the inactive brain cells, which in turn helps mobility, language, dominance, sight, hearing and tactile competence. I don't know if anybody has ever heard of this before. It is done in the Institute for Human Potential in Philadelphia.

We have been doing this since 1966 and we have found a very marked improvement with our children. Some of them who were not able to move about, or talk and walk are now talking and moving around.

It is an experiment, and it is not geared to help every child, but we have found remarkable results with some of our children. Some of them are now going to a normal school after being on the programme for a year or two. We put them into classes in the home into which they fit, and as they progress, they go out.

The children taking part are from 3–12 years at the moment, but our whole school is doing this programme. At certain periods of the day it is carried on in the different classrooms. We cannot do the movements with the older children on the table, they are too heavy, so they just do the creeping and crawling. With the smaller children we are able to do the movements on the table.

We do drama, dancing, music, playing the steel band, woodwork, handicraft and the children produce on a large scale. At the end of the year we have an exhibition and sale of work.

All trainables take part in the programme. The untrainables cannot, but they are doing play therapy; fixing blocks together and different things.

We have a developmental profile from birth to eight years old, and we evaluate using simple equipment, the functional level of the child.

Our older children are employed part-time on our staff, and some are placed out in jobs, doing tailoring, mechanics, domestic work and clerks in stores.

Mr. Edward Johnstone (U.S.A.)

I would like to ask this audience how many are familiar with the Institutes of Human Potential often known as the Doman Delcato method. This is one of the most controversial procedures in the United States today. It has its pro nents and its detractors.

I hold that there is no such thing as an untrainable human being. The measurement of growth and training and progress may be on a very crude and large scale, but when you stop to think that you can train horses and dogs, I refuse to agree to the fact that you cannot apply some training to even lowest forms of human intelligence.

To refer to **Nursing homes**. There has been a great burgeoning of nursing homes in recent years in the United States, and they are beginning to enthusiastically embrace the matter of mental retardation. The great hazard is that they treat the retarded like nursing home cases.

Mr. R. Eichstaedt (Jamaica):

I was wondering, if a country has one facility for the mentally retarded, and this is for a wide range of retarded and different age levels, and the priorities of the country do not allow for group homes for retarded, and maybe there is no interest in a private nursing home for the retarded, what can be done with this institution to make it less of an institution?

Mr. Johnstone:

That's a question that is bothering many people today. Efforts are being made to establish under the roofs of these congregate institutions that you speak of, what are termed modules. In effect this is setting up tight little categories so that you don't have the interaction with the large groups.

This presents certain problems too. You are going to lose some space and so a 100 bed ward may wind up with a total capacity of 70 in the various modules.

Sister Gemma Camacho:

With the educables we have an age range from about 12 to 18 boys and girls. They go to school, they share the same classes, but they do work separately. Socially they are separated. We have the higher grades in one section, then the medium grades and the lower grades, each doing something different. The higher grades are now doing music and domestic science. But all of them do handicrafts. They also go out to parties at the Hilton Hotel, cinemas, sea-bathing, etc.

Mrs. B. Marsh:

I think Sister Camacho has made the point that although this home is residential they do try to become involved in the community. I wonder if other people would like to discuss whether it is possible, or whether you should think about using community services, rather than the residential institution services for the training of the mentally retarded.

Following on to that question, I would like to ask that as an alternative to institutional care, should we consider things like foster care, day care centres, and what could be done in this area? We know that there is a great problem for people to accept children who are mentally retarded. This could be as a result of ignorance or not being educated as to what is mental retardation. I was wondering if we had an all out drive to educate people as to what is mental retardation – not the severe

type, but the more moderate and the simple type of retardation – if we would not have a better response, and children who are put in institutions maybe could be placed in foster care with people.

Should people be trained before accepting a child, so that they will know what to accept and how to cope?

Mr. Johnstone:

Certainly people should have some understanding of the retarded and their needs. Foster home care is definitely one of the alternatives to public institutional care.

We have to look into the feasibility of the utilization of any one or any combination of the points I made earlier. For example if you put a child in the foster home, who would profit by the special classes in the public school system, if there are no special classes in the local public school system, this is self-defeating.

Mrs. Marsh:

I wondered if any of you had a problem with not so much educating your mentally retarded, but educating the public to accept the mentally retarded. It is something that we should look at in considering any kind of placement for the mentally retarded child.

Mr. G. W. Lee (U.K.):

Without doubt the problem of the residential care of the retarded is the biggest single problem facing the world scene.

In England we partly sought to solve it by having a complete coverage of day care centres. So unless there are very exceptional circumstances no child is without provision of a Junior Training Centre, now to be called school, to a senior Training Centre and on to a workshop.

This means that the parents should retain the child in his home until he reaches adulthood. Most parents want this, but they can't do it without these amenities being available simply because it would be a 24-hour day, for almost seven days a week and 365 days a year. But eventually comes the time when the parent is no longer able to look after him as an adolescent or even an adult.

In the past, as in every other country, the British solution was to put him into a large, very impersonal hospital or institution. Now the conditions that you have heard about are not present in the States alone, but in every country in the world.

Our approach is one of community care. Too many people have been put into institutions for no other reason than that they posed a custodial care problem. They posed no treatment or nursing problem. There is no cure for mental retardation. The only possible treatment is education. You don't get education in a hospital or much in an institution. Therefore our approach is one of community care.

Those who need no nursing should be out in the community. The accent is simply one of normalization, and it is normal for people when they are young to live with their parents. And when they are older they leave home. In Sweden they make it almost a matter of conscience that parents should give up their children when they are adults, on the basis that it is not normal to live with your parents after the age of twenty, even if you are retarded.

Therefore the alternative as we see it is the hostel. We are still left with the problem of personnel.

We feel that the answer to this is one of pure job satisfaction. There obviously can be no satisfaction if you are confronted with fifty people to bathe, wash and clothe, put into a breakfast, lunch and a supper situation endlessly.

We feel that a new form of nurse should be created. He or she will be partly nurse in the old-fashioned sense, but much more a psychologist, an educator and a social worker. This should give essentially job satisfaction.

In the north of England, we have had what we call a revolving door hospital, where mothers are invited to give up for the day very low grade cases of mental retardation. At the point of entry they are confronted by a whole battery of physiotherapists. The basis of this is that no recumbent child will be allowed to lie for more than one hour. After that, he will be up on his feet.

This quite new concept has caused so much interest and enthusiasm among the staff, that in fact there is a tremendous queue of people wanting to join this particular hospital.

Mother Joan Teresa (Trinidad):

What success have you had with this programme as regards rehabilitating the very low grade type of patient?

Dr. Allen Miller from New York mentioned that they were doing some research into the matter of very low grade patients, who perhaps at the age of twenty-one after seemingly long periods of training suddenly started looking after their own hygiene etc.

Mr. Lee:

This experiment has achieved a tremendously encouraging measure of success.

Tizard pointed out that a nurse could be forgiven for whipping a child up in the morning from bed, shoving it on the pot, taking it off, having done it by rota to about ten others, putting its pants on etc. If she did it enough times for the day, she could whip through something like twenty in the space of half an hour. You can't blame her for resisting the suggestion that she spends that one half an hour on one particular child. However, when that time was found, the impossible happened: an imbecile was capable of doing his own toilet training, and in fact, could look after himself, with the consequent pay off to the hospital on the one hand and the hospital staffing problem, and above all the satisfaction to the child.

Marion Smith (U.S.A.):

Regarding training of the parents to take care of the child in the home – virtually the only such training in the United States takes place in one of two places. Firstly from public health nurses who come into the home and counsel the parents, and aid them in taking care of the moderately and severely retarded in the home. The U.S. public health service does provide a certain degree of this.

A second means is in the voluntary health aids such as the Retarded Children Association where the parents meet together and get counselling in special sessions or exchange information, or have staff people give presentations on techniques for taking care of the retarded.

Salvation Army School for Multiple Handicaps (Jamaica):

I would like to outline briefly what we are trying to do. We are only one year old, and we have taken children who are doubly handicapped to start with, and sometimes multiply, because

they are deaf, partially sighted and brain damaged.

The child is resident for five days in the week. The parent is invited to visit, and to observe what we do with the child. Over the week-end the child goes home to his normal setting, so that the connection with a normal home life is not entirely broken. We hope eventually that when the child is too old to remain in a school situation, the parent will be so familiar with what has been done that he can take over naturally from us, and the child won't need to be institutionalized eventually.

RECOMMENDATIONS

1. Appropriate and workable alternative to congregate institutional care should be rigorously pursued and utilised.

2. All out drive to educate general public as to the nature and causes of mental retardation and also to involve our various governments in these programmes.

3. Need for special classes in our public school systems.

4. More community care needed e.g. day care centres, fostering out, adoption work, workshops, etc.

5. We should profit from mistakes of other larger countries – the state should never seek to make provisions in terms of large institutions.

6. All professional people should be geared to assisting families with counselling in dealing with problems of the mentally retarded in an effort to keep the mentally retarded child in his own home.

SESSION III

The Adult Period

Plenary Session: Topic 5

"The Employment of the Retarded"

by

Bernard Posner
Deputy Executive Director,
President's Committee on
Employment of the Handicapped.

September 8, 1970

On the front of the stately white Archives Building in Washington, D.C., these immortal words are inscribed for all to see: THE PAST IS PROLOGUE TO THE FUTURE.

With all respect to the Archive Building, I should like to rephrase those words more realistically: THE FUTURE IS PRISONER OF THE PAST.

Think for a moment! Those hot impractical neckties we feel obligated to wear at all times and in all climates – we do so because many centuries ago one of our ancestors had the bright idea of wrapping a rag around his neck to keep off the flies.

We've conquered the flies, but our sweaty necks still are prisoners of an old custom, older than recorded history.

And those women's skirts that are dropping below the knee this fall – women will wear them because they are prisoners of fashion designers who, in turn, are prisoners of the past. The designers either want women to dress like their mothers used to dress in the good old days, or they have been watching too many Barbara Stanwick movies on the late late show.

If these were the only evidences of our bondage to the past, we could grin and forget it. But the problem spills over into other areas of our lives, mental retardation included. It becomes serious.

Employers are prisoners of the past in the way in which they evaluate and measure their workers, retarded and non-retarded alike. They still are using the Nineteenth Century yardstick of productivity to evaluate their employees in the Twentieth Century. In doing so, they hurt the chances of the retarded.

To get hired and to stay hired, the key question is: how productive are you? The speedy worker gets the edge on the job – just as his speedy grandfather got the edge on the job during the days of the sweatshops.

Even the United States Department of Labour pays consideration to the one factor of productivity, when it grants certificates exempting certain handicapped workers from minimum wages. The question is not, "how's your work in general"? The question is, "how's your production"?

This stress on productivity reduces the chances for the mentally retarded to compete for jobs. If only we could shake off the shackles of the past, we would see that today, work is far more than productivity alone.

There's reliability. There's turnover – how often does he change jobs, and how often do you go to the expense of recruiting replacements? There's absenteeism – how often does he take time off from work? There's morale – does he smilingly make others feel good, or is he a grouch who casts a grey blanket over all who get near him. These are some of the factors we should use in truly measuring a man's worth in the labour force; the multidimensional factor of the total man. Productivity alone doesn't mean much if the man stays home on rainy days, sows seeds of discontent with those around him, ups and quits when he feels like it. So I propose a total profile of a worker, taking all factors into consideration. Productivity could count for so much; length of time on the job, absenteeism, attitude, and on down the line. Once we start measuring workers as total human beings and not as cogs in a machine called "production", we shall find that we have improved the chances of the mentally retarded to compete for many lesser-skilled jobs in the work force. These are the kinds of jobs that in many countries are plagued by high turnover, high absenteeism, low morale. I'll concede that in productivity alone, the retarded sometimes may lag behind, but I also insist that sometimes they can run rings around other workers in terms of loyalty and faithfulness and spirit and the other factors we've mentioned.

Employers are prisoners of the past in another way. They keep insisting on some fictional beings called "best man" and "best woman" for the job. To get the "best man" and "best woman" they sometimes give strict physical and mental exams that screen out all but the very bright and all but the very healthy.

The trouble is, for many jobs – particularly of a lesser-skilled nature – these "best men" and "best women" may not be best at all. Would it be asking too much to suggest that employers stop thinking in terms of "best" and start thinking in terms of "adequate?" This new word might open up some doors to the retarded.

Employers are prisoners of the past in still another way that affects the mentally retarded. Many of them set aside entry-level jobs – the kind the retarded could perform – for promising young workers, as the first rungs up the ladder of success. These employers are caught up in a "rags-to-riches" syndrome of the past Century. If Abraham Lincoln, Andrew Carnegie and Horatio Alger could pull themselves up by their bootstraps, so can you. But the rags-to-riches days are vanishing. A study from New York University showed that the chances of an entry-level worker rising up the ladder are only one in ten. So what happens to the other nine? Why not use other more modern ways of encouraging bright young workers to get ahead – intern programmes, management trainee programmes, the rest? Why not give more mentally retarded workers a chance at some of those entry-level jobs?

So much for employers? Now I want to turn my attention to professionals. I can do this best by telling you what happened to me one day last month, when I visited a certain city in the United States as a mentally retarded person, seeking employment in a sheltered workshop or elsewhere. A young rehabilitation counselor accompanied me. We wanted to test, from the inside out, the attitudes of that city's professionals toward the mentally retarded. We stopped in at a dozen places in all. Here are the highlights:

We visited a plant that manufactured cement blocks. When the counselor told the personnel director that I had been in an institution for the retarded, he led us into a private room and closed the door. He looked steadily at me, but he spoke to the counselor. "Can he work with others? It's all teamwork around here." The counselor assured him I could. "What kind of jobs did he do in the institution?" The counselor told him. He handed the counselor an application form. "Here, ask him to fill this out." Finally, we left the office, without my having spoken a single word. Yet I had the feeling the personnel director would have hired me – only he would have told the counselor before he told me.

We visited a laundry. Here, the personnel officer was a bright young man with a sharply pressed suit. He shook hands with the counselor. He didn't shake hands with me. "We don't have any jobs that he could do," the personnel officer said to the counselor. "I just hired a couple of fellows like him. They're doing all the unskilled work we've got around here." He and the counselor talked about future chances. After a while, the personnel officer had an idea. "Tell you what," he said. "Take some application blanks back to your office. Whenever you get a suitable client (yes, he used the word "client"), like this fellow, he can fill the form out in your office and you can bring it here." The counselor thanked him and said good-bye. I said good-bye and put out my hand. The personnel officer looked right past me and walked back into his office.

We visited a candy manufacturer. Here, the personnel manager

led us into his office. "You sit here," he told me, motioning me into a chair by his desk. "And you sit here," he said to the counselor, pointing to a chair on the other side of the room.

"What kind of work did he do in the institution?" he asked the counselor, even though I was sitting right next to him. I had had my fill of being treated as a nobody all day long, so I blurted out the answer. It didn't matter. Again, to the counselor and not to me. "How old is he?" Again, I answered. "I'm fifty". I'm really fifty-four, but I didn't want my age to stand in the way.

Still again, to the counselor: "The owner of this company wants us to hire the handicapped. Maybe we could use this man." Now, for the first time, he spoke directly to me: "Here's an application form. I want you to fill it out. Now."

I wasn't used to being spoken to. So I panicked. I couldn't remember the name I had been going under all day. I couldn't remember the name of the institution where I had come from. I couldn't remember where I was living in the city. I looked appealingly at the counselor. He got the message.

"Look, so we don't tie up any more of your time, why don't we take this form back to my office where he can fill it out?" The personnel manager agreed. We left.

On our itinerary were two sheltered workshops. I'll tell you about one of them.

The counselor introduced me to a woman who just oozed motherly concern in a third-person professional manner – as a nursery school teacher might ooze motherly concern for her little charges. Yet she was young enough to have been my daughter.

"Do you think you would like to try woodworking?" She asked me. "We have to be very careful in woodworking so we don't hurt ourselves." Then she added: "We do assembling here, too. We take this little screw and we put it in this little gadget, like this. Do you think you could do it? We can't make any mistakes, can we?" I agreed weakly.

Finally, after leading me through the workshop, she brought me in to the workshop supervisor for a personal interview. I sat across his desk, facing this man, nearly seven feet tall, completely bald, suspicious eyes, rumbling voice. I had a feeling that this Yul Brynner of the workshop would swallow me alive if I so much as made one false move. Again I panicked, and forgot the name I had been using. I forgot everything except those flashing black eyes. I asked to be excused for a moment. I found the counselor. He returned to the office with me, and explained that we had to leave but would probably be back later. We left. My shirt was wet with sweat.

I don't have to belabour the point, do I? These professionals all were prisoners of the past, prisoners of an attitude toward the mentally retarded that pre-dates the great strides forward in rehabilitation and education and employment which have been made over the past few years.

These professionals still perceived the retarded creatures fresh from the institution as overgrown children (and there's nothing as unappealing as an overgrown child).

Why couldn't they have seen the mentally retarded as people? Why couldn't they have accorded the mentally retarded with the human dignity that all people are entitled to?

Recently, I spoke at a conference on mental retardation, for professionals of all sorts. I was describing how the mentally retarded had been able to do this and do that in the labour force. I was interrupted by a man in the audience who called out: "Sir, I wish you wouldn't call these children 'mentally retarded'."

I felt like answering, "And sir, I wish **you** wouldn't call these mentally retarded adults 'children."

Many retarded, too, are prisoners of the past – largely because we have imprisoned them with our own attitudes and concepts. We call them "children" in front of their faces, these retarded adults, and then we wonder why they react as children. We deny them the human dignity with which we regard our peers, and then we wonder why they lack the self-dignity which is the mark of adulthood.

We treat them as immature adults and they become immature adults. And their chances for independence in the work-a-day world are lessened. They end up being able to do the work of a job, but not being able to cope with the social situations which surround the job.

To be honest with you, at the end of one full day of posing as a mentally retarded person and undergoing a dozen dehumanizing experiences, I myself began to feel less than human, unsure, inept.

Let us break loose from the chains of the past in our perception of the mentally retarded. No matter how we ourselves have been conditioned, let's give them dignity. These are not children; these are our brothers and sisters.

In front of our eyes, the mentally retarded are becoming emancipated. New techniques of habilitation . . . new approaches of education . . . new emphasis on meeting their needs . . . meetings such as this one in Jamaica . . . new opportunities for their independence, in sheltered workshops and in competitive employment . . . a new day dawning, a day that started a mere ten years ago.

Discussion

"The Employment of the Retarded"

Chairman: Senora Garcia Cabrera (Puerto Rico)

Reactor: Mr. Ainsley O'Reilly (Hotel Training School, Jamaica)

Mr. Ainsley O'Reilly:

I agree with Mr. Posner's speech about employing the mentally retarded, but there are some qualifications.

Here in Jamaica our educational standard is extremely low. I would not call them mentally retarded, I would call them "mentally under-developed." But coming to the mentally retarded, I think that the hotel can use these people, for example in the back of the house area, wash-up stations, packing of dishes, etc., things which are very manual that do not need much brain work. But a few problems crop up. For example, one major question, "Can a mentally handicapped person be personally blamed for his actions?"

I will just give an example; in a kitchen where a mentally handicapped person follows everything that the chef or the

sub-chef says, and a union is involved, I am speaking about Jamaica. There is a go-slow and the mentally handicapped person is annoyed and he reacts. Can this man be blamed? A normal person of course can be blamed. This would be a Court case. That is the first question I have to ask.

Secondly, what about the reactions of tourists and employees who find out there are mentally handicapped people helping in the catering section? How would a tourist who is usually an extremely finnicky person react to the fact that maybe the dishes were washed up by a mentally handicapped person? How would the employees themselves react?

We in Jamaica today are not catering to a sophisticated society that we had say ten years ago. We are catering to a society that wants value for its money.

First of all we would have to educate the Jamaican people into the belief that mentally retarded people can do a job in a hotel.

Another point. Everything concerning employment is governed by the Ministry of Labour. I know for example that certain hoteliers would jump at the opportunity to have a mentally retarded person in his place, because he is not going to argue back with him, and actually tell him, as certain employees do today, what he must pay him.

Now these are the salient points. How is the Jamaican public, how is the Jamaican employee, for example the one who jumps from job to job, going to react to the whole thing?

Miss M. Kenrick (Ja. Employers' Federation):

Firstly, how would the tourists react to having mentally retarded people working in your kitchens? This will only be known if you tell them. They very rarely go into the kitchens and ask.

Secondly, the Ministry of Labour. I don't see how they come into this because you are quite free in Jamaica to employ whom you wish. There is no law or anything to say you must get your labour through the Ministry of Labour and any hotel that wants to have a mentally retarded person would quite easily take somebody on.

I do agree with you that you may have some difficulty with the Trade Unions.

I can see no reason why you should have a special Minimum Wage for the mentally retarded. After all if they are not going to be absent, get on with their work, not be missing, not go smoking, all these compensate for the other things that other workers do, and I think that this could quite easily be worked in.

Speaking as an employer, the minimum wage in the hotel trade is quite low, and could not possibly be put any lower. The people working in the kitchens would not of course get tips.

As regards the go slow, I can't again see any difficulty because if your workers go slow you just throw them all out, mentally retarded as well as the rest. If they saw the other workers walking off, they too would walk off.

There are certain difficulties, attitudes of other employees, and this I think would be the greatest handicap in Jamaica . . . the attitude of Jamaicans to somebody who is not quite "it" is unbelievable, and this goes from the top to the bottom generally. Until you can change the Jamaican's attitude to the mentally retarded I don't know where we can go. And it must be an educational programme. Once you have educated the public, the employers will fall in and I am sure lots of employers will help any mentally retarded people if they are asked in the right way.

To come back to Mr. Posner's talk, I thought personally that the method of getting a mentally retarded person employed deplorable. They surely should have gone along to each manufacturer and said, "I have a gentleman who is mentally retarded, aged 50 or 40, who can do so and so and so, would you please interview him?" And then I think you would not have felt as you felt. This actually has been done by the Salvation Army here for their blind people.

Dra. D. Sarasola (Dominion Republic):

In her working experience in Santo Domingo, she has found that some employers would hire people coming out from the Sheltered Workshop just because of their emotional liaison with the workshop, but not because they were truly convinced that the retarded can actually do the work that he is supposed to do. For that reason they are trying to enforce a policy, asking all the entrepreneurs who have more than 100 employees to make available at least one position for the mentally retarded.

We should study some field of work that requires analogous methods of techniques. For example if somebody learns to hold a tube in one way, they can also water the lawn. These basic hand movements and things like that should be identified, so that the mentally retarded person has more opportunity for work. If he fails in something he can always rely on what he has learnt – on the basic technique.

Dr. M. Thorburn (Jamaica):

So far we have only had about three people go out into employment from our school. One went to a woodwork shop and did fairly well. The tourist industry is one of the most important industries in Jamaica and many of the islands. I would like to know whether for example, Barbados, Puerto Rico, or the Bahamas has any experience of having people employed in the tourist industry.

Mrs. Joan Coronel (Aruba):

In Curacao they do more handicrafts, whereas in Aruba at the four schools we have for mentally retarded much handicraft is learned, but not much is sold as tourists' items. It is more to learn the trade. These people are employed as carpenters helpers, maybe as carpenters, masons, unskilled labour, and we also have quite a few employed in the tourist trade in hotels, in the kitchens as dishwashers, bell boys, helping around the pools, and we also have some of them as waiters. Many of these boys are the friendliest waiters you can expect.

When certain tourists come in and you have the feeling that they really want all they can get for their money, these boys are called aside, and they only help local people. Local people mostly enjoy their help because they are really friendly and if something goes wrong, well you are happy because you expect it in a way, and you can laugh it off. But they are employed in the tourist trade and it seems to be going fairly well.

Dr. Fontaine (Venezuela):

The mentally retarded can wash dishes and they are satisfied by doing so. But how does a normal human being feel if he has aspirations to do something else and yet he is condemned to wash dishes all his lifetime.

Senor H. Garcia (Puerto Rico):

What are the co-operative organizations doing in Jamaica, in

the Caribbean as a whole to provide employment to the mentally handicapped. I think that the co-operatives, due to the nature of their philosophy would be willing to accept mentally handicapped persons to work in their organization. I was thinking that we could consider the possibility of organizing handicapped co-operatives ourselves.

In Puerto Rico there are actually in some co-operatives mentally handicapped persons working in the organization.

Mr. E. Johnstone (U.S.A.):

There is one area of employment of the mentally retarded, which I have attempted to promote for many years. That is jobs in facilities providing services of a special nature. These would include institutions for the retarded themselves, mental hospitals, T.B. sanitaria, nursing homes, homes for the aged, day-care centres, hospitals, group homes and the like.

Many retarded adjust to and accept tasks that the so-called normal employee finds repugnant, you know, like washing dishes for the rest of his life. I submit that this conference take cognizance of this great potential labour force.

Mr. Francis Hardy (Buffalo):

I should like to tell you of a programme which we conducted this summer.

We had about four educable girls who had reached the end of their time in school. What were they to do? There are not many opportunities, even in a city as large as Buffalo. So we decided to train them as teachers aides for trainable classes. We have produced four of the finest aides that any teacher could possibly have. One of the features is that they are not going to carry tales to the parents.

It has been very successful and we are now going to try and incorporate it into our college programme.

Mr. Johnstone:

I would like to endorse this from my experience. The job opportunities are with us.

Mr. Scope (Curacao):

In the Netherlands Antilles there is a law that 2% of the working population must be recruited from the mentally retarded.

We have in Curacao nine schools for mentally retarded and this is very many because there is a population of 140,000. There is also a special agency that trains mentally retarded, and finds employment for them in stores and so on.

In the schools for mentally retarded, the boys are trained for handicraft, bakers, carpenters, masons, etc. and girls are mostly trained for work in the kitchen. They have a school for domestic science and I must say that many people are very happy to have domestic help who have been trained at these schools.

The Netherlands Antilles as a whole are trying to keep up with Holland to have 2% or 3% of all people employed in industry recruited from the mentally handicapped, because 2% or 3% of the population is mentally handicapped.

Mr. Cecil DeCaires (Barbados):

There has been no activity in this direction so far, in Barbados, and I think we must take the blame for this. I hope that there will be good possibilities of making headway in this direction because most of our tourists come from Canada, America and Europe and we have found that in whatever exposure they have had to the mentally retarded, they are usually very sympathetic and helpful.

Last year a national committee was set up in Barbados, sponsored by the Manufacturers' Association. They got together representatives of the Employers' Confederation and the Chamber of Commerce, Government, the Service Clubs, Rotary, the Lions and the Jaycees and our association was also represented. I am glad to say that already we have been able to place in employment in the Garment Industry three pupils from our school. It is a modest start, but it is a start in the right direction.

Mr. B. Posner (U.S.A.):

Tourism has become a number one industry in the world. It now exceeds wheat. This is very important for the Caribbean. There are going to be opportunities in this field for the retarded if there are enough facilities to train the mentally retarded, not to do the jobs, but to be able to get along with people.

It is quite meaningless to throw open opportunities and say the retarded shall work, if the retarded has not been prepared for work. So the first step has to be in the area of preparation.

Mr. Ainsley O'Reilly:

There is one question I should like to ask. In the other West Indian islands and in the United States, what percentage of unemployed do we have? I know that in Jamaica it is extremely high. I don't want to sound like a pessimist, but the hotel industry in Jamaica employs thousands of people. I remember when we started the hotel school, our one advertisement in 1968 yielded some 850 applicants. These people were not employed. Now, I don't know personally if in Jamaica we employed the mentally retarded in the hotels, where would the normal be employed? Is there going to be some sort of reaction on the part of people who are not employed?

Mr. Francis Hardy:

Dr. Thorburn asked about other fields in which we have people employed. We have some working in bakeries, in the hospitals and the hospital staff prefers our so-called retarded "children" to their normal employees because of many things that have been mentioned already. We have a messenger service that they conduct on our university campus. In New York City I know that they are using them to do messenger service around the city. They are being used in offices to run duplicating machines. They can package cards and there are many, many things in this area that they can do.

There are many facets of office work that they can do. Mr. O'Reilly has mentioned there are other employees who at times resent it. Again it is a question of educating the general public.

Miss M. Kenrick:

I am a little concerned when thinking of mentally retarded people as different from anybody else. They are different, but they are all human beings, and therefore in the employment field, I think the best man for the job should be employed; whether he is mentally retarded, unemployed or white, black, yellow, green or anything.

I don't think we have to worry too much about Jamaicans being unemployed and then employing some of the mentally retarded. But with those retarded in active employment and the trade unions, do they have to become trade union members?

Mr. B. Posner:

It is a complex question because there is no uniform answer. In some industries in the United States the mentally retarded do join the unions like anybody else. In other industries locals have been very nice about exempting the mentally retarded from all the usual procedures that union members must go through. They created special categories for the retarded to permit them to do entry level jobs and stay there, if this be the height of their achievement.

Generally in the United States the unions have been more than helpful in helping management and government and the whole field of rehabilitation, and helping the mentally retarded get a foothold in employment.

Dr. Thorburn:

Obviously it is necessary to have public education directed towards the trade unions, as well. Before we start to approach any industries we should start on the trade unions first.

We have a very large field of employment in domestic work and one has continuing problems in this field. It gets more and more difficult. This is one area we might explore.

Mr. B. Posner:

We have tried that in the United States. Domestic work for the mentally retarded has not proved too successful because of the supervision that people need and the amount of judgement they may have to exercise individually. But there are successful experiments with house cleaning teams, etc. coming to your house under supervision and doing the entire job for you.

RECOMMENDATIONS

1. Identify occupational tasks that require the same basic skills, so that mentally retarded persons be given more opportunities to secure a job.

2. Withold the rehabilitation certificate until the retarded individual has secured a job and has passed the probation period.

3. Influence public policy to require employers who have over 100 employees to hire a proportion of mentally retarded.

4. Approach Co-operatives to employ retarded.

5. Educational programme for dignifying the handicapped and unskilled labour in primary schools.

6. The delegates make official approaches to all of the organisations engaged in the employment of people to give favourable consideration where this has not already already been done, to the employment of the mentally retarded.

7. A survey be made of what is being done in employment of retarded in the Caribbean, and their success and this be circulated to all members.

SESSION III

The Adult Period

Plenary Session: Topic 6

"Sheltered Facilities and Occupation for the Mentally Handicapped"

by

George W. Lee

Secretary General
The National Society for Mentally
Handicapped Children of Great Britain

September 7, 1970

If one searches the records it is quite clear that the right of the retarded to work is clearly established.

The United Nations in its declaration of Human Rights in 1946, laid down that every citizen of every land has the right to work and the dignity of labour.

The I.L.O. in 1955 reinforced this proposition. In 1968 our own International League for Societies for the Mentally Handicapped, at their Jerusalem Conference, brought out a declaration of special rights of the retarded, which are additional to the rights of the ordinary human being.

However, this is not only one way traffic; even the retarded have obligations. And the right to work carries with it the obligation to contribute. From this it follows that it is wrong to bring about a regime of over-protection, and to put the retarded of whatever degree in the situation where they are being amused or meaninglessly occupied. In fact, this right means the obligation to work, even in such a small way as to make a very little contribution to their own upkeep, and not to be just occupied.

The British approach can be dealt with in two parts, the ESNs or educable – I.Qs 85 – 50 and the trainable – I.Qs 50 – 12 or severely subnormal.

The educable person goes from the school at the age of sixteen or seventeen to the training work situation to have a socialization course that equips him for life in the community. This is important because we often find that disaster comes when a person who has been all his life in the shut-in atmosphere of a special school and suddenly finds when pitchforked out into the cold world outside that he is unable to stand the rigours of the climate. These courses are provided either by the local Education Authority or by the voluntary society such as my own.

From that point he goes into open industry. There is no question of a sheltered workshop, or very rarely, for an educable person. In England everyone has the right to go into open employment.

We are really concerned here with the trainables. Where they are available they come from the nursery, creche or kindergarten situation from the early age of two to five into the Junior Training Centre. They go on to the Senior Training Centre and then at the age of sixteen, seventeen or eighteen years to the sheltered workshop, and you would be very surprised to know that in the case of severely sub-normal people, quite a number of them are going into open industry.

Then two famous research workers – Clarke and Hermeline – when considering the employment potential of imbeciles – best typified by mongols – came out with a proposition that in simple tasks the main distinction between their performance and that of normal people, is not so much the end level achieved, as the time taken in this process. In other words, in simple tasks, if you give them enough time, the retarded can produce marketable goods which compare quite favourably with those produced by normal people.

Another proposition is that the initial inability of the retarded person has little relation to levels subsequently achieved in training. Tizard and Grad in 1962 indicated through their research that employment problems of the retarded are not wholly different from those of other handicaps. Quite remarkable work was being done at that time in Dutch workshops in mixing chronic psychotics, physically disabled, burnt out schizophrenics and the like with simple retarded people. And in fact all research at this particular level does indicate that you are likely to be more successful in working with retarded people if you mix them.

Professor Clough who has done a good deal of work in England on the subject of employment and potential of the handicapped came up with the conclusion that the main obstacle in the way of their employment was not so much their potential to produce as their social acceptability, this is I think a fundamental point. If you have a potential worker in any work situation and it can be proved that he is capable of making a meaningful contribution you may be hesitant if that person is so low in his social competence that he cannot fit in either with normal people around him or tell the time. Social competence is the most important thing therefore that you can teach any retarded person. The ability to recognize money values, to recognize signs like STOP, HALT, BUS, LAVATORY, LADIES, GENTLEMEN, TELEPHONE. These are the things that the retarded should be taught if they are going to enter into work.

Now it was with this consideration in mind that the National Society in England seven years ago decided that it would embark on an entirely new experiment. It plucked from the hospital situation fifteen girls and fifteen boys between the ages of sixteen and twenty-six and placed them into two hostels and a workshop.

At first they were scared of living in what was really community care. We put them under a mother and father figure, and we said virtually you are members of these two particular families They all had their own chores and every day they went to the workshop.

Now the object of the workshop was essentially to assess their potential. The whole idea was to put them through a variety of tasks to give them manual dexterity, recognition of the nature of materials, recognition of certain tools that could be used and generally to acquaint them with the conditions that they would find if they could reach sheltered employment.

It was so successful that we were overcome by parents wanting more of their children coming into these hostels and the workshop.

Most of the young people became quite remarkably released from inhibitions from which they had formerly suffered and to our astonishment, not only were they able to make a meaningful contribution to their own keep, not only was their potential raised to a marked degree, but something like ten or eleven of them got jobs in open employment after 1½ years spell at this particular workshop. The girls got jobs in local launderies and the young men got jobs in garages and in local industry.

The difficulty is that this was geared to an industrial situation and this sort of thing can only be done in a country where you have a multiplicity of small industrial processes. Where these do not exist, then of course it is hard to repeat this sort of experiment. However a lot of these jobs are being threatened by mechanisation.

There were difficulties in socializing these young people e.g. in teaching them how to use the telephone, to take a bus by themselves, going on a long journey by train. Life is going on faster than many of the retarded can keep pace with especially with modernisation, decimalisation, etc.

To deal with the difficulty of utilizing the potential labours of the retarded, we have now set up a second experiment in an entirely different vein. This is in Somerset. Here we are attempting to assess the potential of low grade cases of retardation in rural pursuits. This means in agriculture, horticulture, market gardening, parks and gardens' maintenance; and in ani-

mal husbandry. This experiment has now been going on for a year. We are watching it with considerable interest. But it must be borne in mind that it is no use creating or drawing out of a retarded person a skill which cannot be used in the situation to which he is going to return.

You may not be aware of what can be done by low grade cases of the mentally handicapped. In a Dutch workshop you see at the one end the simplest of all tasks being performed by exceptionally low grade cases ranging at the 12, 13 or 14 level. This is the reclamation of old government envelopes, simply by getting a sticky label, running it over a wet roller and sticking it on the envelope. Also the assembly of ball-point pens, tiny parts of terminals for the Dutch telephone system, and then on to the production of tennis shoes. This is quite remarkable, but you are even more astonished when you see the ultimate in what can be done by retarded at the 35 – 40 I.Q. level in the production of Philips components for T.V. sets. You may think that this is impossible. You have people marrying up red terminals with an electric soldering iron to the red wire, and the green wire married to a green terminal and so on. And each part is separately handed over.

Not only is this a remarkable demonstration of what can be done, but it also means that the retarded themselves have a tremendous sense of uplift. They know that their work has meaning. They know that when they are in a real workshop they are made to stamp their cards and they go through all the business that the state requires of paying insurance and the like. This gives them a complete sense of identification with the normal world and brings satisfaction to them and of course to their parents.

Coming nearer to home here in the West Indies, I think that you can profit by the mistakes made by countries who have been in this business for longer. You can also profit in terms of the workshops that in a very short space of time you will set up.

We are now facing the problem of automation. We are looking for other jobs for the retarded not only in the rural pursuits but also in the production of fine craft work. This has to be finely made and designed by an expert, created with imagination, and with an eye to what the tourist buyer wants.

Finally all over the world we are going to be faced with one of the greatest problems now facing mankind which won't be how to work, but how to employ your leisure in a satisfactory meaningful way. This also applies to the retarded. How do you enable them to cope with the leisure time that is available to them and is already, unhappily, available to many of them who have no jobs at all.

We see it taken care of by the Gateway Club movement. This started three years ago in England, and we have been wondering what hit us, because there was an explosion. It is a truism that even if you don't know the extent of the need, if you make something available, you will soon know just what the need is by standing back for the rush of people who want to avail themselves of the service. This is obviously very true of the Gateway Club Movement.

In England having announced our intention to form it we were deluged by people saying "Can you help us form one of these clubs?" So we have quite the remarkable spectacle of something like four or five clubs being created every week, with something like 100 to 150 people in each club. That is quite a remarkable accretion of membership.

What is particularly gratifying about this movement is that it is a two way movement. We seek to solve the problems of the retarded in their leisure time by bringing in normal young people in the community who are otherwise having a somewhat purposeless life. This works magnificently. We have hobbies, handicrafts, model making, music, concerts. This is due to have a culmination in the First International Festival of Gateway Clubs in the spring of 1971 in London. The reason we are having the festival is because the First World Symposium of the International League on the leisure-time interests and pursuits of the retarded is to take place in London.

There is a very special role for voluntary organisations in the field of mental retardation. No country can say they have all the answers. I think we can say that in Sweden they have the best residential facilities. In Holland we can undoubtedly pay tribute to their remarkable workshops. In England we have pretty comprehensive legislation and we have now reached the happy stage when no retarded person is unable to find some sort of amenity.

But this is the world of experimentation. We have all got to learn how to deal with this problem, and who can experiment better than a voluntary organization. Governments tend throughout the world to be conservative. But a voluntary organization, especially a consumer organizaton can afford to stick its neck out. If it makes a fool of itself no one minds. If it hits the jackpot, then the Government will take it up. This is the way we go forward and progress. I therefore say how exciting it is to see growth of the voluntary movement in this country and throughout these islands.

Discussion

"Sheltered Facilities and Occupation for the Mentally Handicapped"

Chairman: Mr. Marion Smith (U.S.A.)

Reactor: Mr. Ron Eichstaedt (Jamaica)

Mr. Ron Eichstaedt:

I would like to give a short description of the facilities that we have here in Jamaica and what we are trying to do in the way of sheltered occupation.

At present we are trying to train the older children in the school in cooking, laundry work, gardening and also in child care. Once they are sufficiently trained we can get employment for them in the community. But this is going to raise a problem because Jamaica does have a large number of unemployed and we may just add to the numbers. Either we send our retarded children out highly skilled, or we are going to have to find some other means of employment. We can hire them in our school training centre. The girls can be kitchen staff, ward maids and they can also work in the laundry and since our school will have a lot of land, we can also hire some of the older boys to work on the grounds in farming aspects.

Last year the school started a type of sheltered workshop programme. It doe: not compare at all with what Mr. Lee described this morning. Our workshop started with eight boys over the age of 18. The problem was that they were getting too old for the school and there was no programmes for them.

We started with working on small curios made of coconut shell, and also to help in the busier work of the office: rubber stamping envelopes and folding and stuffing envelopes. Our programme had success, but it also had its problems.

One of the problems is that we have lack of sufficient supervisory staff, e.g. we had nobody skilled in woodworking to help us.

It seemed logical that if we wanted to have the boys working with their hands, we had to develop something, and that's the reason for the coconut shell curios and the stuffing and stamping of envelopes.

Another problem with the curios was the selling, but that is now being solved. We soon realized that we could not just rely on the handicraft items. We see now that we are going to have to go into some type of contract work.

Mother Joan Teresa (Trinidad):

We have the problem of the demand being greater than the supply. We have samples of the work done by the children in a showcase. This is advertised and orders are taken, but with bigger workshop facilities in the offering we hope to deal with this.

Our two schools – occupation or training centres – are divided into classes. Half of the day is occupied in academic work and the other half in different types of arts and crafts.

Because of the competition we have in Trinidad from community development programmes with normal people doing handicrafts, their finished product is actually much better than the retarded turn out. But again this is something that with concentration and better workmanship we would probably be able to offset. We are concentrating more on the tourist trade.

Mr. Lee:

When I spoke about mixing with the mentally ill I meant burnt out schizophrenics. On the whole you find that when you overcome the initial resistance of the compus mentis physically handicapped person who may possibly resent working with a mentally retarded person, you find that they all have a nice part to play in the workshop situation. This has worked particula.ly well in the Hague. The blind carries the lame man etc.

Mr. Smith:

Let me answer a question raised earlier. Can a sheltered workshop really compete successfully with skilled workers? I would like to give you a single concrete example of how they can.

I help to run a plant of the Honiwell Corporation in the United States. We purchase goods from a total of 1,400 different suppliers, vendors, sub-contractors, those who supply goods and services to our company. Each year we present an award to the ten best suppliers out of that 1,400. Those who have done the best job of a quality product, delivered on time, which meets all our requirements, and which we can assemble into the navigation equipment that we sell to our customers. For the year 1969, one of the top ten was the workshop of the Association for the Retarded in Clearwater. I want you to know that in our industrial society a sheltered workshop can win a top award from a major industrial corporation.

Sister Maria Teresa (Barbados):

In our sheltered workshop we have thirteen boys. We make ceramic tables and ashtrays, and because of our large tourist trade in Barbados, like Trinidad we do very well in getting a market. The girls are good at embroidery and macramie work, which is in great demand in the West Indies at the moment. Within the last two years we have made about 200 macramie handbags and they were bought particularly by tourists.

The Lions Club have seen that the workshop is too small and this year they won the cup for the West Indies by donating a $35,000 workshop which we hope will be put up by year end.

The smaller children have part-time employment in painting postcards. They are marked on the back "Painted by Needy Handicapped Barbadians." These go very well. They are drawn by an artist and the children paint them. They get about a penny on each postcard. It is just a little bit of painting, perhaps a man with a steel band, and eventually with practice they are able to do about 100 in a day.

In addition to this we are painting faces on stuffed toys. A new factory has been established in Barbados. They stitch up the toys and then send them to us to paint the faces.

Recently, Barclay's Bank has sent us their signs for us to paint.

Mrs. Sybil Blyden (Bahamas):

At present we do not have a sheltered workshop although we see there is a great need for it. We have tried with the older people over 18 to integrate them into jobs in the community, that they can do. They go to work in the morning and come back in the afternoon. This is necessary as if the person does not adjust to the situation, he would still have a sense of belonging and can still remain in school.

There are some people who do not adjust. Three people who were over 20 were placed at the rehabilitation centre for mental patients in their occupational therapy department, and here they do different types of crafts. We have boys who have gone into a turtle shell factory who sort ear-rings and we have had good reports from those.

Government has granted us some land, but the school is still under a voluntary body, the Bahamas Association for Retarded Children. In the plans drawn we would have residential cottages.

Mr. Lee:

Mr. Smith asked "How do you know when you need a sheltered workshop?" You always need one if you have a group of people who are retarded and of the age to work. From age 16 onwards, you should have a workshop. It is an essential amenity.

Why? No one has failed to register the tremendous sense of satisfaction on the faces of children or young people who are engaged in some sort of creative activity. If there is also a reward, then the satisfaction is doubled.

Another reason is the economic factor. All the countries of the world have to face the fact that there is a certain suspicion and lack of understanding of what retardation is on the part of the public at large. If they feel that the retarded are parasites on society and it can be demonstrated they, through the workshop situation, can make a contribution towards their upkeep, then the society will accept them the more readily.

The first problem is essentially money. You have to plan how much even the most modest workshop is going to cost. Whatever you plan, you should think of it in stages. Most workshops after they are created almost invariably are faced immediately with the problem of how they can expand. Therefore the funds should admit for a stage situation. I would have thought that funds can be raised by local endeavour of those who are taking the initiative in creating the amenity.

The first priority after drawing up your plans and getting a workshop going would be to count on the goodwill of local employers for contract labour, contract work of some kind.

You could also think in terms of service work. For example there seems to be an inexhaustible demand all over the world for concrete blocks.

Dr. Williams:

We are now in the process of planning a sheltered workshop. We have the money for the building and equipment, and we have been very fortunate to get somebody who is very knowledgeable in this field, who has been working in Barbados who is a Guyanese who has been exposed to what can be done in the United Kingdom.

Mr. Smith:

First I think that one of the keystones of success depends heavily on public awareness and education. To go back to the first point made by Mother Joan Teresa; **Find out what will sell before you make it.**

For instance it was found out in Florida that soft drink bottling companies have a terrible problem getting the wooden cases. One workshop went around to the local bottling companies, offered them a very good price on restoring the wooden cases and they just have a going business because they provide that. They have surveyed the market. They defined the need before they tried to fill it.

Mr. Eichstaedt:

I have a question for Mr. Lee; is there a place for additional training within the workshop or even recreational programmes?

Mr. Lee:

Our attitude is slightly less concerned with production. Of course it is a workshop. It is not a play centre. But we can see that they have slightly different needs from other able-bodied people. We take them out of the workshop situation from time to time to give them some sort of recreational break, and put them through the socialization course. How to tell the time, how to recognize words e.g lavatory, stop, go, bus, telephone, etc – all this sort of thing, and to teach them to use the telephone, to cross the road, and generally what to do when they get home. All these things that make it possible for them to make their way to work and live together meaningfully.

Dr. Garrett (U.S.A.):

I should like to make three points.

1. In using words like **educable** and **trainable**, these words have absolutely nothing to do with the world of work but everything to do with the world of education. All too frequently, particularly where we try to have this continuity between school and work, we are mixing words which have to do with one setting with another. This is a very great disservice. I hear the word **child** still being used around here when it is primarily youth and adults who are going out to work. This is extremely important, because all research with which I am familiar points very clearly to the fact that there is no relationship between measured mental ability level and capacity to engage in constructive remunerative occupation. I should like to underscore the point that the qualities which made for successful occupation are not your education, but those personal qualities of loyalty, devotion and ability to have respect for the property with which you are working.

2. With reference to why does a sheltered workshop exist in the first place? Everything I have heard here suggests that the only purpose for a workshop is in order to produce goods and to return money to the pocket of the individual. There are other purposes and Mr. Lee has emphasized one, that is to help people in achieving skills in inter-personal relations. But this does not just happen. This happens only because you manage the atmosphere of your workshop to achieve this particular purpose.

So I would suggest to you, is the workshop for evaluation? Is your workshop for socialization? Is your workshop for vestibular training? Is it for the achievement of occupational skill, or is it for the achievement of work habit? There is considerable difference between the two. Whether you are manufacturing articles made of coconuts or sea-shells is not quite so important as why you are doing it. In other words work has a purpose.

3. There is one other factor which we have not taken into consideration, and that is the sheltered workshop as a visible and viable entity. It is the evidence to the world that the mentally retarded are actually able to engage in constructive occupation. Work per se talks for itself.

Mr. Smith:

In the workshop scene we have been guilty in the United States to some extent of over-selling our ability to successfully and permanently place the mentally retarded in open industry. We have been just a little bit too optimistic and we fail to realize that a large percentage of the mentally retarded will not be able function in open industry, and therefore, some of the more successful work opportunities that I have seen are two phased sheltered workshops.

Stage one or area number one is for relative permanent employment in a sheltered environment.

Stage number two would be that which perhaps prepared good or furnishes services in a sheltered environment, but is deliberately aimed at readying the individual to tackle a job on the outside. But the successful guys are those that realize that there are going to be failures. For some reason he cannot function successfully outside and we need to create an environment to which he can return without prejudice, or without being labelled failure, and that he can continue to function adequately in the sheltered environment.

Dr. Williams:

One of the problems we have been facing which you don't face in the bigger countries is the unemployment situation.

Mother Joan Teresa:

We have in our institution and in affiliated institutions over twelve of our past trained patients in paid employment. Actually in the Lady HoChoy Home we have two as gardeners, paid the normal pay, and also others employed in the kindergarten in the school and as ward maids. Girls also live outside in hostels, because the Carmelites also run hostels.

Mr. V. Serritella:

In Jamaica, the Association for the Deaf operates somewhat of a sheltered workshop in addition to having five firms that supply us with contract work. Because of the wide open labour field in Jamaica and the wide open wage system, many times this concept of basically paying the handicapped worker less than his co-worker in organised industry can work to your advantage, because many industries are willing to provide transportation, trucking facilities etc., to get goods to your workshop in exchange for lower output etc. They don't have to pay as much money to establish you. In our experience, we have not had

any problem with organized labour, in fact, both of the major unions in Jamaica endorse this wholeheartedly because we are taking up slack in many areas. There is one great disadvantage in that it makes the contract work a bit harder to keep economically viable, because you don't have the influx of funds coming in that labour does have, and you are cutting down on their overhead, while you are adding to you own.

RECOMMENDATIONS

1. Public awareness programmes aimed at local employers to stimulate contract work for mentally retarded.

2. Information of successful workshop experience in Caribbean be collected and disseminated to those considering their establishment.

3. In the Caribbean context, where there is a low level of industrialization and widescale unemployment our planning should be towards creating our own self sustaining and productive industries, rather than in trying to use the workshop as training ground for the retarded to go out to compete in the labour market.

4. Where local employment conditions permit consideration be given to employment of suitable non-resident retardates in public and private institutions.

SESSION IV

Adjustment

Plenary Session: Topic 7

"The Families of Mentally Handicapped Children in Trinidad"

by

Dr. John Neehall
Consultant Psychiatrist,
St. Ann's Hospital,
Trinidad.

September 8, 1970.

This investigation was a pilot study of the families of mentally handicapped children. It is meant to be a preparation for a more comprehensive study, which I hope to undertake in Trinidad, the aim being to throw some light on the problems faced by these families.

As far as I know, no research on this subject has been carried out in Trinidad before. Although I undertook this as an academic exercise it is just possible that the results of the full-scale survey would be of some value to those who are concerned with the organization of medical and social services of these unfortunate children.

The children of the study I undertook were all idiots and imbeciles as described in the Mental Deficiency Act of England and Wales in 1913, 1927, and the World Health Organization 1927 Manual and corresponds to the English classification of severe subnormality as defined in the English Mental Health Act of 1959. They would also fall into levels 3, 4 and 5 of the American classification.

No intelligence tests or tests of adaptive behaviour have so far been standardized for the Trinidadian population, and it is questionable whether the standardized forms of the tests used in North America and Britain are applicable. I made no attempt to assess the IQ of my sample using any of the formal psychological tests, and relied entirely on behavioural observations. However, the children in the study who are patients of St. Ann's Hospital in Trinidad, were tested about two years ago by Dr. Mary Hackney, a Canadian clinical psychologist who used a battery of tests, including the Wisc, the Draw-a-man Test, the Ravens and some others.

To prevent myself from being influenced by her ratings I avoided reading her report until after I had made my assessments, and I found that all the cases I described as idiots or imbeciles were rated by Dr. Hackney as having IQs of below 50. This supports my feeling that idiocy and imbecility can be ascertained with a high degree of accuracy by studying the child's behaviour, and that mistakes in assessment on this basis are more likely to be made in the feeble-minded categories – that is in the above 50 IQ group.

Two criteria were used in selection. The child must be below fifteen years and severely sub-normal, that is with an IQ below 50. They were selected from the Children's Ward of St. Ann's Hospital, Trinidad, the Psychiatric Outpatients' clinics, and the Lady HoChoy Home for the mentally retarded. Forty-four children were studied; twenty-four were living at home with either one or both parents, and twenty were institutionalized.

Information was obtained from records in the hospital and from interviews with a member of the child's family, usually the mother. I found the hospital records to be of very limited value, and most of the information was obtained from interviews with the mother or the nearest relative. In all cases the interview was carried out in the parental home so that the interviewer was able to observe for himself living conditions, and in the case of the home sample, the child's behaviour.

There was a standard method of interviewing. After explaining the purpose of the interview, the parent was allowed to talk freely about her child, and then later on, a schedule consisting of forty-six questions was gone through systematically.

In the vast majority of cases the parents were most co-operative and welcomed the opportunity to discuss their child with someone whom they thought would be able to give some helpful advice.

In one case I encountered a complete denial by the parent of their mentally defective child who is now a patient in St. Ann's Hospital. He has never been visited by his parents. From information received from residents in the neighbourhood, I am absolutely certain that I found the right home and the right parents. Their professed ignorance of the child was categorical and the interview was discouraged in a most hostile manner.

On the whole, however, the reception by and the co-operation of the families were very good.

Now information obtained by interview is always open to criticism. One must always be suspicious of its validity, and it is difficult to assess the reliability of what one is told.

By making the questions as factual as possible, I tried to reduce error, but the nature of the study was such that much depended on judgments, attitudes, opinions, etc., and although I tried to be objective in rating responses to questions on social contacts and problems of management, etc., this aspect of the study is open to severe criticism. I have, however, tried to explain the principles I used in rating by giving anchoring illustrations.

Results

Forty-four mental defectives were studied – twenty-five males and nineteen females. Two were from the same family, so that a total of forty-three families were studied. The mean age was 9.6 years. I was able to make a clinical diagnosis in only a small minority of cases. Four had mongolism, one had severe jaundice at birth with a history of mild jaundice at birth in other members of the family and two had a history suggestive of brain damage at birth. The defective was an only child in 7% of the families, the firstborn in 31% of the families and the last born in 36% of the families. In ten of the fifteen families with the mental defective as the last born, there were four or more sibs in each family.

Thirty-four of the forty-four mental defectives I found to be in good physical health. Twenty of these were living at home and sixteen were in an institution. An example of poor physical health was a six year old girl, weighing twenty pounds severely physically handicapped, unable even to lift her head, mute, suffering from chronic bronchitis, asthma and epilepsy. An example of good physical health was an eight year old mongol living at home and attending the Lady HoChoy Home as a day patient. She had a well-developed physique without any signs or symptoms of physical illnesses, and no history of any serious illness in her previous records.

Speech Defects

Sixty-two percent of all children studied had a moderate or severe speech defect. Fifty percent of the home sample had no speech defect at all. And only 25% of the institutionalized sample had a speech defect.

Epilepsy

Twenty-five percent had epilepsy, 40% of the institutionalized ones and only 12% of the home sample.

Family Characteristics

Twenty-four of the total number of families had a mother and father in the home, twelve had broken homes. In seven families the mother and father never lived together, and one had a visiting father. There was a wide range of numbers of children in families at home ranging from 1 – 12. The average of the

size of the families was 4.8 children.

The mean maternal age at the birth of the defective was 28.6 years which I think is lower than what has been found in other countries e.g. Britain and the United States.

The mother realized that the child was defective before the age of one in fifteen of the thirty-three families. In ten, the child was between three and five, and in two cases the child was over five years. In fact in one case the child was twelve years old when the mother realized that he was severely sub-normal.

Maternal physical health was, on the whole, quite good, Maternal mental health in ten of the twenty-four mothers who had their mental defective children at home, I found to be poor, and the majority of these were suffering from severe depression. Some of them were actually attending the psychiatric clinic. Three psychopathic mothers had left their children in an institution and never bothered to look for or even to visit them again.

What are the effects of the mentally defective on family life? It was of course not feasible even to attempt, let alone distinguish between the effects on family life ascribable to the presence of the mentally defective and those effects due to other factors. The parents were encouraged to talk about the effects of the defectives on their family life, and specific questions relating to their social life, the attitude of neighbours towards the mentally defective, the parents' feelings of shame and embarrassment, guilt, blame, etc., were asked. On the whole, of the twenty-two families in which the mother and father were living together, eighteen described their homes as happy homes, and four as unsatisfactory, but the defective was never blamed for any deterioration in the marital relationship. As a matter of fact, in four cases the parents felt that the defective brought them closer together.

As far as the broken homes were concerned, since only one of the parents was interviewed, in each case, the one who remained in contact with the child, it was not possible to arrive at a balanced judgment of the part the defective played in the disruption of the family life. But it is interesting to note that none of the ten parents – eight mothers and two fathers interviewed – felt that the defective was in any way responsible for the separation. Forty percent of the defectives who were at home had an adverse effect on the social life and studies of the other siblings.

In most cases the mother strived to minimize the adverse effect on the normal children, although in 60% of cases, the mother admitted to direct questioning that she neglected the other siblings because of the defective. Only one of the forty-one mental defectives who had brothers or sisters suffered any overt hostility from the other siblings. In twenty of the twenty-two families with the mental defectives at home, the other sibs were friendly and protecting. On the other hand, 40% of the defectives at home were aggressive or violent towards the sibs.

In 80% of defectives living at home, neighbours were described as friendly, and the remaining 20% suffered only a little unkindness. None of them were ridiculed or laughed at. In 66% of all cases the defective was sometimes left with neighbours when the mother wanted to go out. Forty-five percent of mothers felt ashamed or embarrassed. Eighty percent tried to overcome the embarrassment and took the children out with them frequently. The remaining 20% rarely took their defectives outside the home.

In the vast majority of cases the parents did not bother to seek any genetic counselling about future children. In thirty-seven of the forty-three families, they just continued to have more children and only in six cases did they discuss with their family doctor whether or not they should have any more children.

Attitudes to Institutional Care

There were 15 defectives in St. Ann's Hospital and five in the Lady HoChoy Home. The mothers were asked the reasons for putting the child in the institution. In most cases there was not just one reason, but a combination of factors which resulted in the removal of the child from the home. A behaviour or management problem was given eleven times, housing seven times, a broken home five times and financial problem seven times. Twelve of the mothers were dissatisfied with conditions at St. Ann's Hospital, two were satisfied, and one could not make up her mind. Most had no regrets however.

For example, Raymond, aged twelve was the first of seven, the youngest being one year old. All the children lived in one room with their parents, in a dilapidated shack without electricity or water. Raymond's parents were happy to leave him in St. Ann's Hospital indefinitely.

Patrick, aged eight, was the tenth of ten siblings. His father has chronic kidney disease and is unable to work. His mother is a domestic servant. The family of twelve live in a two-roomed house. Although Patrick's parents are very dissatisfied with conditions in St. Ann's, they have no choice but to leave him there.

Mona, aged nine, was the tenth of thirteen siblings. Her father died in December last year. Her mother is unemployed and suffers from coronary insufficiency, gall bladder disease and when I saw her, she was very depressed. Mona's mother brought her to St. Ann's requesting admission on the advice of her doctor, but when she saw the conditions in the Children's Ward there, she promptly returned home with her child.

Summary

Forty-three families of forty-four severely sub-normal children were studied. They were all under fifteen with a mean age of 9.6. The general physical health of the defectives was good in 80% of the cases. There was a severe speech disturbance in 43% of all of the defectives, 55% of the institutionalized ones and 33% of the home sample. Twenty-five percent had grand mal epilepsy; 40% of the institutionalized ones and 12% of the home sample. Eighty-two percent of the total sample had a moderate or severe behaviour problem, and all of the institutionalized defectives and 66% of the home sample had a moderate or severe behaviour problem. Speech disorders, epilepsy and behaviour problems were found to be of greater frequency in the institutionalized sample than in the home sample.

Now the prevalence of severe subnormality in England and Wales is between two and three per thousand. No surveys have ever been carried out in Trinidad, but if we assume that the prevalence is the same there as it is in the United Kingdom then there will be between 20,000 and 30,000 imbeciles in Trinidad and Tobago. Less efficient obstetric care, larger families and lack of genetic counselling make it more likely that the prevalence in Trinidad will be higher than it is in the United Kingdom. On the other hand, the higher infant mortality rate would have the opposite effect. Be that as it may, there is no doubt that the medical, social and educational service for the mentally sub-normal leave much to be desired. There is a great need for epidemiological studies, not only of

mental deficiency, but of all types of mental disorders, because I do not think that realistic planning of mental health services can be done successfully unless it is known what the needs are.

At the outset of this study, one of the aims was a comparison between the families of the defectives in hospital and the families of the defectives at home, and all the data was broken down into these two groups. The samples, however were too small for detailed comparisons using the chi square statistical technique, and that is the reason why I presented the information in the form of percentage frequencies.

While one must guard against placing too much weight upon the absolute frequency of any particular finding, I think that percentage frequencies can give an idea of the relative magnitude of various problems and indicate avenues for further study.

In discussing this paper, I should like you to bear in mind that it was based on a simple pilot study, the purpose of which was to give the author some experience in field work and to bring him into intimate contact with the family, with the problems of these families and to explore avenues for more detailed study in the future.

Discussion

"Family Adjustment to the Retarded Child"

Chairman: Dr. Robert Gray (Jamaica)

Reactor: Dr. A.C. Graham (Barbados)

Dr. A.C. Graham (Barbados):
I will try to relate some of Dr. Neehall's findings to Barbados.

General Physical Health:

I think that in any part of the world, the more retarded you are, the more likely the person is to have some degree of malhutrition, and this can be obesity as well as under-nutrition. I think we have a similar problem in Barbados.

Speech Disturbances:

We have no speech therapist in Barbados, and as you will remember, if you do not have a service, you do not know what the problem is. Epilepsy is possibly less than 25% in Barbados. One of the two most important points – 82% presented moderate or severe behaviour disorders. Compared with the figures from North America and the United Kingdom, this is very high indeed, and can mean only one thing. We need to give a better service to the patients themselves and to the family.

The next thing. The high incidence of poor maternal mental health. This again points out that we have got to give a better service.

It is interesting that the effect on the siblings was not very severe, and this is in keeping with the open society in the West Indies, to an extent mental retardation is accepted rather easily. We have got to find ways of reaching these families and helping them in the area of behaviour problems and maternal mental health.

In Barbados we have sixty children in the Challenor School, with a waiting list of 150 plus. These are people who have been seen either at the school or by me and we have accepted them tentatively as educable or trainable. I am ashamed to say that we tend to put them on the list and forget them, until there is a vacancy. Now this is not good enough. What we do need is a parent education programme.

How can we do this? Home visiting, and here we should make use of the district nurses. We might be able to have a newsletter. We could make use of films and mass media. Incidentally we would also be educating the public as well as the parent. This is something that we can do immediately and should not take a lot of money. There should not be any great barrier to it, and I feel that this is one way that we can attempt to reach these large numbers who are outside the school.

Dr. Robert Gray (Jamaica):

One thing that would arise if you were to take up Dr. Graham's suggestion about the parent education programme is that I am sure that very soon after you started such a programme you would suddenly find a lot of severely subnormal children on your doorsteps, and ready to enter your study. This in fact has been the experience in Jamaica since we have started doing a little bit more advertising ourselves, especially in preparation for this conference.

Miss Olive Drummond (Jamaica):

Do you have any method of overall screening of babies, or how did you select your samples for the study?

Dr. John Neehall (Trinidad):

I don't think there is any screening of babies in Trinidad. I selected my samples by going through the ward at St. Ann's Hospital, the Children's Ward, and picking out the children whom I thought were severely subnormal. Also by visiting the Lady HoChoy Home.

Dr. Graham:

In Barbados the majority of babies pass through welfare clinics, and quite a number of children are referred around six to eight months because they look peculiar or they fail in milestones. I was amazed at the knowledge the normal mother has of child development. That is the first screening time.

The pre-school child will be caught when they fail in language. In the school children it is when they enter school, or fail after a period of a year or two in their acquisition of reading and writing.

Dr. F. Williams (Guyana):

I should like to ask Dr. Neehall what really motivated this study?

Dr. Neehall:

Within recent months I had a number of children referred to me by the doctor who examines people who are trying to go to the States because he suspected that they were mentally subnormal. I was surprised at the tolerance of the mothers. Secondly, the children's ward at St. Ann's Hospital is in a deplorable condition and I felt that recommendations should be made to the Government about improving the conditions.

I learned that the waiting list for the Lady HoChoy Home runs into several hundreds. So the problem is a big one. I thought that the first thing one has to do is to discover what are the main avenues that one should explore.

I was struck too by the fact that very few of the mothers got any advice from the doctors about the possibility of further defectives being born. Perhaps it was because of ignorance, but the matter was not even discussed with them. In the present state of knowledge we are still not in a position to give dogmatic advice to a parent, but I think that with the advances that are being made today in chromosomal work and in biochemistry, in the next decade or so we will be in a better position and we should prepare our general practitioners and our population for the time when this advice will be available.

Dr. R. Gray:

I think this last point is very important, and must play a part in any services which are provided for parents of retarded children. There is one family at our school in Kingston who has 4 microcephalics. Nobody had said to her, "Look, it is time to stop."

Una Tapper (Medical Social Worker, U.C.H.):

I wondered as you worked with the parents if you got any indication that they were willing to do anything to improve themselves and their children as a group, or they were mainly concerned with their individual problems?

Dr. J. Neehall:

I can't answer that, because I don't know.

Dr. R. Gray:

I have the impression that in Jamaica it is really more from the individual point of view that they approach the doctor. It is another of our important future duties, that as an association for the mentally handicapped we should promote the interests of the parents as a group, because it is only from them that further advances will be made.

Mr. V. Serritella (Jamaica):

With regards to Mrs. Tapper's question. We do have two separate parent groups within the association for the deaf. As a social worker who is primarily concerned with group work, we find we have a great deal of trouble interesting parents, and forming a cohesive group in social action projects. They are ready to get together to watch a film, for parties, but the purely social group work it is extremely hard to motivate parents, no matter the social class. We have one group of parents, from a higher social economic class and one from the lower one. We have the same difficulties with both groups.

A study in the United States in 1965 concerning children and families with all handicaps showed that the level of concern usually went along with the type of service that parents were pushing for. Social workers generally found within this category that if the parent was concerned about getting his child into a residential setting, the concern was higher up to the point of the child actually entering. If the parent was forced to take a day setting, they found that apathy did set in after a period of time. I was wondering if any of this came out within the small pilot study that you did.

Dr. J. Neehall:

I found that the interest in the child was keener in the case of those who were attending as day pupils than in those who were institutionalized, especially the Lady HoChoy Home.

During the first few months of their stay in hospital, the child was frequently visited by the parents, but after a time interest lagged, sometimes because other children were born.

Mary Whitnall (Jamaica):

I am exceedingly concerned that in all the ideas and resolutions that have come forward at this conference there has been no suggestion of prevention of mental retardation. I have in mind thorough pre-natal care, for example, injections against German measles, careful examination and records of possible risk, a mother with toxemia, and closer liaison between medical and educational workers.

Dr. Woo-Ming (Guyana):

I could make one comment in the light of trying not to repeat the expensive errors of the developed countries. Criteria for high risk infants have been used in the United States and Europe to find out which are the children who would eventually develop learning problems. Only about 10% to 12% of these children who might be called high risk actually develop learning problems. So this would be a very expensive project for us, with not a very good case finding result.

So what I was suggesting in my talk was that we should try to find these high-risk environmentally retarded children in the first two years of life and spend the majority of our resources on this group which actually in most studies are only about 7% to 10% of the poor children rather than trying to spread our resources thin in all 100%.

Dr. Neehall mentioned behavioural problems, and hyperactivity, I was wondering if the three panelists and Dr. Williams have been using Ritalin for hyperactivity and with what results, and whether they have been using behaviour modification for behaviour problems in the retarded.

Dr. R. Gray:

In Jamaica we have heard about "Ritalin", and the good results that have been obtained, but we have not really made any study of it as yet.

Dr. F. Williams:

Some of my paediatric colleagues have been using amphetamine and I have been using another new drug "Neulactyl" very successfully in hyperactive children.

Dr. J. Neehall:

I have been using amphetamines for hyperactive children for the past seven years, without any serious side effects. I am so pleased with the effects and I am so familiar with its use that I am reluctant to change to Ritalin which does not seem to have any advantage over amphetamine.

Dr. Gray:

Another important environmental factor, as far as Jamaica is concerned, is probably malnutrition, which, despite what people think is still very common. And the earlier the malnutrition occurs, and the longer it stays for, it appears that there is a definite relationship between malnutrition and brain damage of some sort which may result in mental retardation, and this is an eminently preventible condition in children. This of course requires economic and social change.

Dr. A.C. Graham:

I think that education is the most necessary thing to stop this 80% behaviour disorder. I can't remember which member of the group mentioned that 60% of children in a remedial school – a Borstal type school in one of the islands were found to be educationally sub-normal. I will heartily agree with this. It is at least 60% in Barbados. If a child is referred to me because he is running away from home and spending nights out, the first thing I think of is mental retardation.

In the West Indies, there is a tendency for very strict parental control, the result is that the child breaks, many of them have headaches, abdominal pains; or they react to the stress situation in behaviour disorders, which may be delinquent.

Dr. Woo-Ming:

I want to endorse what Dr. Graham was saying. We have the additional problem in the States in parental over reaction – first of all they get the idea that the children will always remain infants, and then they over-protect and so we have children who could be very well toilet trained, who could be very well talking, who are not so because of the parents deciding to devote their entire life to their welfare.

In Columbus State Institute a psychologist has been trying to get mothers involved in a fairly stringent behaviour modification programme and we have been doing some of this ourselves, trying to use positive reinforcement to modify the children's behaviour. In theory this sounds very well, and it does work, provided you can convince the parents. It might be worth our while for some people either in psychiatry or psychology or even other physicians to learn of some of the methods of behaviour modification if behaviour problems appear to be as common as Dr. Neehall has found.

The other recommendation I should like to make is to do some work on attitudes both of parents and of the community. Since we have decided that we are going to try to habilitate these children, the success of habilitation will depend on the attitude of the community if there still remains a very large stigma about mental retardation in the community. If you are going to work on public education, this is obviously where we have to start, to find out where we are.

Dr. Neehall:

Behaviour therapy is all well and good in Canada and the States and the United Kingdom where you have a case-load of ten to twelve patients, but in the West Indies where there are so few psychiatrists and the demand is great, we just have not got the time to expend on behaviour therapy, and we have to depend on drugs.

Miss C. Hanna (Bahamas):

We are concerned about the prevention of mental retardation. I was wondering if work had been done in the field of genetic counselling. For example, in the Bahamas we have a deaf school where 99% of the children are in the same age group. They are all the result of maternal rubella. Also a lot of our mental retardation are from three outer islands. This is all the result of inter-marriage – first cousins and even closer, Now, I am wondering if there had been an intensive programme of genetic counselling perhaps, if it could not have been prevented, the parents might have been more prepared.

Dr. R. Gray:

There is no formal clinic which offers genetic counselling at the University or anywhere else. The closest we have got to this is really through the interest of Dr. Thorburn who has been doing the chromosome work at the University Hospital, and in fact it was through chromosome studies that she eventually became involved in the mentally handicapped. We do give genetic advice in the clinics, where appropriate. We have thought about starting a "birth defects clinic". This would be the place where genetic advice could be offered. We also had an epidemic of rubella in 1965 which has left a large number of affected children.

RECOMMENDATIONS

1. The institution of a parent education programme based chiefly on the home.
2. Setting up of a project for the study of preventable aspects of mental retardation.
3. The institution of a study of methods for control of behaviour disorders.
4. Setting up of a project on the study of attitudes of parents and the community towards mentally retarded children.
5. Institution of a programme of mass education with regard to normal child behaviour development.

SESSION IV

Adjustment

Plenary Session: Topic 8

"The Adjustment of the Community to the Mentally Retarded"

by

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The place of the retarded in society and the adjustment of the community to them must in the final analysis be considered on a highly individual basis – both for the persons and families affected and the specific communities in which each resides. No two personal and family situations, nor their milieu, are exactly alike. Moreover, the nature of the problem and projected optimal solutions are never static, but change with the ever-shifting economic, technological and social conditions in which they must function.

In countries where the typical farm is still a small plot of land, and where all the work is of a simple unskilled manual nature, the retarded adult is a distinct economic asset to the success of the operation. Social conditions and demands are such that he can cope. This situation is changing rapidly everywhere. The current emphasis, by many governments is to educate the farmers to combine into larger co-operative units, enabling the adoption of more modern and efficient technological methods, with the result that the increased skill demands will create major adjustment problems for the retarded adult and his family.

By contrast, in many of the larger cities of the world the retarded are provided with a range of special education and training service and placed in sheltered workshops because as yet industry doesn't absorb them. Some of these countries have very advanced, technical services for the retarded.

Yet, the mentally handicapped boy on the small, relatively primitive, farm operation may be better adjusted in his community – and the community to him – than those who have had the benefit of special services but face greater obstacles in coping with more complex situations which their urbanized communities present.

Common to all countries in the world is constant and accelerating change in economics, education, technology and social behaviour. This is not peculiar to the so-called "emerging nations". Approaches considered ideal five years ago, are regarded as inadequate today. Physically isolated special school facilities envisioned as the ideal in some countries are now being questioned because they reinforce or perpetuate the concept that the retarded cannot function with their normal peers. Initial special academic-oriented emphasis is being replaced by preparation for life approaches such as schoolwork and junior vocational school programmes, as we recognize the subtle but significant benefits to be derived from integrated programmes and discover more effective techniques for training retarded to adjust to the complex demands of modern life.

In the initial phases, pioneering organizations and individuals preferred isolated programmes as a way of demonstrating potential results. We now realize that such programmes can become established institutions within the community, and that their very existence can serve as a barrier for the normal and retarded to learn to adapt to each other, thus effectively preventing optimal community adjustment.

Unintentionally, in our desire to help a disadvantaged group, we create a series of isolated programmes and facilities which supposedly provide more effective training, but in the process, remove them from the environment which would allow for bilateral adjustment e.g. building special isolated schools for mildly retarded. Some of this is necessary because it maybe the only way to demonstrate to the public that the retarded can be helped. If such developments occur in the absence of a philosophy of the whole life needs of those we are trying to help, we end up with an array of specialized facilities which may be very costly but fail to have optimal effect.

What then constitutes an adequate approach for optimal adjustment of the retarded in their communities and vice versa? The objective is to make the retarded as normal as possible.

There is common agreement that the retarded should not be isolated from the family and community setting and that he should have the same rights and privileges as his normal peers to realize his potential. This means that he should not be the victim of sympathy and charity but be accorded opportunities to realize his potential in the same manner that society accommodates others who form minorities: the physically disabled or handicapped, the veteran, the heart disease or industrial accident victim.

The second component of the normalization concept is society's attitude and level of expectation . If we don't want society to treat the disadvantaged as creatures of sympathy and rejection, then we must face the reality of societal demands. Society makes a distinction between its productive and non-productive members. Its primary attention is to those who are most productive. This is a phenomenon of the innate protective mechanism – a means of survival or a way of realizing greater progress toward a higher standard of existence. Religious social and humanitarian principles also play a role in that they stimulate sympathetic attitudes and charitable support for its weaker and disadvantaged members. Tolerance of the handicapped has varied throughout history according to the economic ability of a tribe or nation to support them without sacrificing the security or life needs of its normal people. This situation prevails today, though generally it is more subtle and less extreme than the absolute abandonment or even extermination practiced in ancient times.

Public attitudes determine a community's behaviour toward the disadvantaged. But economic ability to render support is an important factor. Thus, governments will refrain from providing equal consideration to such a group on the grounds that it must preempt its resources to assisting the needs of the majority and those who will contribute to greater productivity. Health and welfare programmes generally receive consideration after much higher priorities such as general education, construction of roads and economic development needs are met. It is essential therefore, that we demonstrate the economic value of providing services to the retarded.

An outstanding example of this approach is the development of medical and vocational rehabilitation programmes for the physically handicapped, the industrially injured, the wounded war veterans, the blind and deaf and those with psychiatric disorders.

Voluntary organizations pioneered the rehabilitation field but major community involvement followed concrete evidence that the application of knowledge and skills on a multi-disciplinary basis could transform the crippled dependents into full or partial gainful workers.

The same arguments can now be made for this field. In the opinion of eminent authorities, the problem can be reduced by half if we effectively apply the existing knowledge and skills at our disposal. Thus, we have a powerful potential weapon with which to publicly argue our case.

Another cause of negative public attitudes is fear and ignorance about the retarded. Fear stems from ignorance. Without eradication of these two destructive factors there is little hope of the retarded being accepted in the community. It may be possible to generate enough private gifts and governmental support to maintain specialized facilities and programmes, but this stigma and rejection of the retarded will persist. Paradoxically, public **sympathy**, which can be generated by appealing to the emotions is in fact a negative and undesirable element in the retarded gaining a rightful place in their social milieu, even though it can

serve as an interim step towards development of more accepting attitudes.

A knowledge of the psychology of public attitude formation and change, and the sequential techniques to be applied is fundamental to planning a comprehensive programme for adequate community involvement with the retarded.

Negative attitudes are the product of the factual and non-factual information which people have about other people. We sometimes help to create negative attitudes in our publicity by depicting only the more involved retarded (the minority prevalence). In the absence of other knowledge, the public generalises that this is representative of the problem.

By appealing to their humanitarian instincts, we can gain public sympathy and support. Too often, we stop at that point, or, even worse, we continue to reinforce their negative attitudes by financial campaigns and public service messages which emphasize charity or with slogans like "Help those who cannot help themselves". Likewise, by separating physical facilities for the retarded from those serving the normal, we further convey to the public the notion that the retarded cannot function in partnership with the rest of the population. I don't want to be misunderstood. For practical purposes it is usually necessary to begin with a segregated facility – it is often the only way to get started. My concern is when this is repeated beyond the necessary demonstration phase.

Undue public sympathy is destructive to healthy personality development of the handicapped. The retarded must learn to live in a normal attitudinal environment where they are expected to perform in a competitive society to their optimal ability. The public should be taught to expect realistic levels of performance. In turn they will be accorded equivalent rights and privileges. The most powerful agent in public attitude change is direct exposure to the object of the prejudice.

How do we go about implementing a plan of adjustment of the community to the retarded?

One must avoid taking short-cuts which produce immediate but only partial solutions. I refer to the frequently expressed plea of parents that if only the professionals and government accepted responsibility, the problems of the retarded would be resolved.

Governments will respond to direct pressure but only to the extent that it feels it has general public support. In the long run, the best way to get adequate government action is through a public which really understands the problem, accepts the retarded for what they are and insists on action. Citizen action groups are the primary and most effective vehicle through which to obtain the support of the general public, the professional community and the governmental authorities.

The dramatic results produced by parent groups throughout the world is well known. But too many have or will fail to provide the leadership needed beyond their initial exemplory pioneering efforts because they too frequently limit their involvement to parents of the retarded and to managing a school or sheltered workshop.

The primary cause of such planning and organization errors is our failure to either truly understand the real nature or significance of that powerful, internal human force known as attitudes and the effect these have on our behaviour.

It therefore seems appropriate to reemphasize some of the fundamentals. Attitudes are a protective mechanism in animal and man and thus control all our behaviour. Negative attitudes lead to cautious behaviour (avoidance, rejection and defence). Conversely, positive attitudes result in behaviour characterised by trust, confidence, support and acceptance.

Attitudes are emotional in content. For example, the public imagine that all retarded have abnormal physical features. Throughout history attitudes toward the retarded have been based on variable beliefs. In some primitive cultures the retarded are treated kindly, even worshipped, because of tribal or religious belief that a supreme power has willed it so. In other cultures they are maltreated (even exterminated). This is not just a matter of uncivilized or ancient cultures. Example: the extermination practices in Germany thirty years ago. These decisions are based on beliefs, feelings, or attitudes and not necessarily on scientific evidence or objective views.

In the final analysis, attitudes are changed through effective salesmanship of large segments of a population via the use of psychological techniques to win support of a group. The **"engineering of consent"** (as the father of PR called it) is the world's biggest business. It sells capitalism to some and communism to others. It makes us accept ideas, things and people which we at one time rejected. There need be no practicality to it. In China (because of propaganda) people willingly sacrifice material things for idealogical objectives – such as fighting capitalism. In North America, television advertising promotes primarily non-basic products and people continue to believe that they cannot afford basic health and social benefits. If a statement is repeated often enough it forms the basis of a new attitude and familiarity can breed contempt but more often it breeds blind acceptance. The art of changing attitudes has reached a level where the top experts feel that given the money, they can change any attitude regardless of initial resistance, rejection or logic or practicality.

What does all this have to do with adjustment of the community to the problems of the mentally retarded? It means this.

1. There can be no meaningful adjustment on the part of the community to the problems of the retarded without a change of attitudes from negative to positive.

2. It means that we have not exploited the real potential of the powerful opinion moulding techniques available to us.

3. It means that we may be confused in our priorities of action, or fail to appropriate our available energy and resources so as to accomplish the goal.

4. It means that there cannot be long term sound governmental and public support without a public which is sold on the right and value of what we believe to be the goal.

   What is this goal for the retarded?

   Is it one of receiving education?

   Is it one of getting a job?

   Is it one of housing for community residence, or a recreation programme or sheltered workshop?

   Is it one of enough trained teachers to do the job?

   Or to make them economically independent?

These are all important – but they are only the means to an end. These things will happen when there is a readiness on the part of society to provide such help. These services ought to be provided not as a special concession – granted out of a sense of charity – but because society accepts them as it accepts other deviant members in the community such as the aged and senile, the disabled war hero, the industrial accident case or

those disabled by heart disease.

How can we argue that isolating the retarded in special schools, workshops and residences close to home, but where society still treats them with charity, sympathy and rejection, makes the retarded any happier than isolating him in a large remote institution where the individual may have less privacy and material comfort but where he does not daily sense the negative attitude on his way to and from the special school or workshop.

How can we argue the case for the value of an enriched environment when we do so little to change the climate in which the retarded spends most of his time, namely his home and neighbourhood. These are often problems which we must take into account in our long range planning before spending all our energy and effort on special services at the sacrifice of the other.

Our theories about assessment, education and training are still very much just theory – not based on absolute proof. Social science theories go in cycles – each has its fad. Experiments are essential to continuing progress and make for a scientifically healthy development. Your obligation is to keep the issues in perspective. By this I mean that we should begin with the point of view of normalization for each retarded person, so that he remains as much in the mainstream of society as possible. This will not happen if we demonstrate to society, by our segregated approaches, that we ourselves don't believe they can function otherwise. Our task is to develop a broad range of action activities which bring about an accepting public. There are two:

1. Factual information about MR in the form of an on-going public education programme (the kind of creditable job done here this past few weeks in Jamaica). It must be done on an on-going intensive basis.

As with the psychology of successful advertising it needs continuing repetition. The parent organizations and some professionals have done a good job but it is only a start.

We must avoid negative public education such as slogans which appeal to the sympathy of the public (e.g. Help them, because they cannot help themselves) we must avoid at all cost the appeal to charity. Contrary to popular belief, it is just as possible to get support from positive messages.

2. Direct exposure to the object of the prejudice. DIRECT contact and observation dispels the doubts, fears, discomfort and distorted images which a person develops about people or things he is unfamiliar with. The best way to recruit volunteers, teachers, psychologists, doctors, businessmen and politicians is to create opportunities for them to be exposed and involved.

These two principles should guide us in the way we plan, organize and execute our programme activities. We can achieve the combined goal of providing special care and keeping the retarded in the mainstream of their local environment. But we must be willing to modify our rigid concepts which imply that the best professional services are in the semi-sterile environment of special and isolated settings. What can we do? We can modify our approaches. Some important lessons have been learned which if applied can help us solve normalization for the retarded – that of preparing the retarded to live among their normal peers and for the community to fulfill its role more effectively.

We can plan programmes which involve the public and the professions and at the same time provide the necessary training and preparation of the retarded.

(i) There is no justifiable technical reason why special classes schools, workshops or residences should be placed in isolated areas separate from normal facilities. Regular houses in any residential area can be rented or bought (and sold) as the need arises.

(ii) Sheltered workshops should be placed in industrial or business areas and attached to regular factories.

(iii) Special classes and schools should be attached to school facilities for normal children.

(iv) Youth groups (of normal teenagers) can be organized to develop and operate social and recreational programmes. These programmes can be conducted in regular recreational facilities.

(v) School-work programmes provide contact with the community and help the retarded and the community to adjust to each other.

(vi) Demonstration programmes should be placed near universities or other presonnel preparation institutions to serve as practicum centres for staff development.

(vii) Membership in the voluntary associations should include non-parents.

(viii) Fund raising should be of the kind as to involve large numbers of people and the appeal should be in terms of ability rather than disability of the mentally handicapped.

(ix) Special transportation should be avoided where possible.

(x) Travel exchange programmes and summer camping (using regular camp sites) are effective vehicles for involving the public. The same applies to sports events organized by volunteers.

These are examples of how programming can be planned to help bring about greater community involvement and acceptance. Some special facilities will always be necessary for the more severely retarded or as demonstration and problem-solving centres.

Voluntary associations should not become burdened down with the operation of facilities or programmes which have proven their value, otherwise they will lack the energy and resources with which to continue their trail-blasting role in an ever-changing world to which the retarded are expected to adjust.

These approaches can be more readily introduced in areas where the special facilities and special professions are just emerging where the resistance to change is not as great as in some of the European and North American countries.

It requires imaginative, creative, intelligent and mature leadership. It requires substantial planning and co-ordination with public and private programmes; with schools and colleges. Too often we pre-judge a situation and fail to capitalize.

A surprising amount and volume of human, financial and physical resources are available here in the Caribbean. One group in one country here cannot do it alone – you need a Working Task Force and a resource centre. You can undoubtedly get substantial money for such a project – if an imaginative proposal was developed which pointed how the community can become more involved and help resolve major dificiencies which exist, at a relatively reasonable cost.

This conference is a significant milestone and can be the stimulus to developing a modern and progressive Caribbean approach to realistic community adjustment to the retarded and an adequate level of services for them.

Discussion

"The Adjustment of the Community to the Problems of Mental Retardation"

Chairman: Mrs. Sybil Francis (Jamaica)

Reactor: Mr. Cecil DeCaires (Barbados)

Mr. Cecil DeCaires (Barbados):

Favourable adjustment to the mentally retarded in most communities has taken many years, and I think it is true to say this even in the larger and more developed countries of the world. It is true of these Caribbean territories. Certainly of Barbados.

Seven years ago, a few dedicated individuals called a public meeting inviting all the people of Barbados to do something positive for the mentally retarded of the island. They were the few who knew the problem of necessity. Then there were the others, who, out of the goodness of their hearts were prepared to help do something about this great problem, though not exposed to it directly. This was the birth of the Barbados Association for Mentally Retarded Children on June 28, 1963.

But what of the community adjustment to this event? "There are no mentally retarded children in Barbados", was the confident comment we heard. They genuinely believed this to be true. I nearly grew to believe it myself.

In 1963 we knew of six mentally retarded children. Ten months of intensive investigation, using all of the known channels available, the parish doctor, the Red Cross, the Social Welfare Department, produced one. So we, with hope for the future, started our school catering for seven children. Since then, the story is the same that you have heard, no doubt, over and over again. It never varies. Today we have sixty children, with a waiting list of over 150.

Where were these children before? You and I know the answer, because this answer too never varies. Hidden away in dark, lonely places, where helplessness and hopelessness were all the future had to offer. Thank God at least they have now been brought out and that 53 more have grown to know the warmth and love of the Carmelite Sisters who run our school for us.

From this you will see that one of the first and most important adjustment of our community to the place of the retarded in our society came from the hitherto, misguided parents of these children, as they learned that there was really no need to be ashamed of their little ones that were different from the other normal children.

Barbados, it can be truly said, has adjusted itself to the place of the mentally retarded in its society, with help and understanding, and love.

In looking at community adjustment I refer to one aspect I have found most discouraging. How regretful it is to see parents of mentally retarded children – particularly fathers – who are equipped to do something positive through active participation in the work of the local association, sit idly by and do nothing. Voluntary organisations have the vehicle to effect massive change if they plan and implement strategies according to proven principles of attitude change. I believe that the strongest single motivating force towards the establishment and effective management of voluntary organisations for the mentally retarded in any community is born of the utter despair which fills the minds and hearts of the people who find themselves confronted with the stark fact that they have a child that is mentally retarded.

Mrs. Sybil Francis (Jamaica):

We have started on this very important question of parent involvement. In the rural areas of Jamaica there are large numbers of children who are mentally retarded, but whose parents have not got the money to send them to the school here – and indeed they have not got the space for them in the school – and for whom there is this feeling of helplessness. I would be very interested to hear the views of this group on this question of education, enlightenment, involvement of parents.

Mrs. N. Anderson-Duncan (Jamaica):

I have been discussing the possibility of involving our nurses in the actual training, or helping with the training of parents of mentally retarded children, especially the country areas where you have the district midwives and the public health nurses. If the training is incorporated in the curriculum, they could make a contribution.

Mother Joan Teresa (Trinidad):

In Trinidad the public health nurses do this as a part of their programme. They have a refresher course doing practical work in the institutions for the mentally retarded. They visit, work with the children, in the classrooms, in the nursing part of the work, the residential part of the work, and have lectures from staff in the institutions. Perhaps you could think of this as a possible way of approaching your problem. And all other groups of social workers come into this, university students and other groups, to get experience with the problems of the mentally retarded. This has helped to create a greater understanding and public awareness of mental retardation.

We have also followed this up with TV programmes, talks to the general public, different groups. As well, we have an active parent organization that takes part in different functions in the home and also have monthly meetings to exchange different problems and get help from trained personnel.

Dr. M.J. Thorburn (Jamaica):

I should like to comment on two things. Firstly, the positive approach towards this problem – putting it over to the community. For many years the old school at Norman Road did not have the appeal to some section of the population. Many middle class parents would not dream of ever sending their children there, partly because of the location and the whole situation. However, in the last two or three weeks with the publicity associated with the new school, applications have come pouring in. Once the people see that there is something being offered, they will come forward. But they don't come forward here until something good is being offered.

Secondly, parent co-operation. During the past years we have had parent group discussions, film shows and talks. Whenever anyone has been in the island who knows a lot about the subject, we have got them to talk. But we get about 15 or 20 people coming to these meetings, and yet we circulate all our parents. Quite often the majority of those people are teachers.

Cecile Johnson (Jamaica):

My problem is what do you do if people come forward and you can't refer them because you know they would not be able to

pay for their children's fees.

Mr. Francis Hardy (Buffalo, New York):

Perhaps in the association there is an individual who would be willing to spend some time to go visit a family and work with them. If the parents are not literate, give them the information verbally. Help them in as many ways as you can to cope with their situation where it is. If they can't come to you for help, you take the help to them.

In your parent groups when you have meetings I think it is imperative that there be two parts to the meeting. Perhaps you will have a professional presentation, but probably the parents will get more out of the chance afterwards to meet together just as parents of children who have the same problems. One more thing, some of the people who work with these children have the wrong attitudes to them. In the United States, I have seen too many teachers of the exceptional child who thought that they were going to get an easy baby sitting job. Some of these so called professionals, need to have a change of attitude too.

Mrs. S. Francis:

Now, if we are going to use the social worker, and others, one of the things that we need very badly is simple literature, directed particularly to the problems existing, rather than the more sort of technical side of it. I wonder if in your parent groups you might do what we did working with a group of grass-roots people in another field, and that is to get them to to prepare a document. We got them to bring up the problems which they had, and out of this came a very useful little document which has been used in other areas. Perhaps you could extend the parent groups by taping sessions, or getting themselves consciously to formulate some of the questions which they have, and get this out in material, I know this would be very valuable to workers in the field.

Miss Doris Haar (U.S.A.):

I would make the following recommendation that all sources of material, printed, movie, film strips, tapes, anything you can get your hands on be tapped, as well as any teaching professional folks in the field of mental retardation, who might be coerced to come to Jamaica. I also suggest that possibly we should even think of a formal liaison between schools of nursing and active nursing associations such as Jamaica Nursing Association, and the schools of social work and associations of active social workers in the islands. All resources could be tapped in this way, whether it be private, through the Kennedy Foundation or the World Health Organization or Kellogg etc.

The University of Miami is most anxious to set up this sort of liaison, and perhaps to have continuing education courses in Florida, and then the problem will be your own transportation over there, but I will leave that up to your own resources. I only say that some of us have been in this business for a number of years, and there are materials that have already been developed, and so I would ask you to just make use of those first.

Dr. Harlold Feldman (Jamaica):

I wanted to emphasise one particular point which I think should not be overlooked, and this is early diagnosis in mental retardation.

Dr. M.J. Thorburn

As Mrs. Francis says a very large proportion of our society are "grass roots". The problem is public education in this area. How do you get the people to get together? We might write articles in the Daily Gleaner, but does it mean anything to them? We really have a problem with basic information and communication there.

Mrs. S. Francis:

In Jamaica certainly we have large resources which are not being tapped at all. I am speaking about the women's groups, church groups, community associations and so on, many of which are often carrying out programmes which are not really very meaningful, and which could be used. We have groups who sit down and do fancy work etc., who could be utilized in these very important areas. Voluntary organizations could be utilized far more in programmes of this kind.

Mrs. Phyllis Campbell (Jamaica):

In the child welfare clinics that are operated in Jamaica, quite a lot of instruction is given to the mother about how normal children are to be cared for. This aspect may be brought in at this time, not emphasised but, introduced as one of the aspects of child care and development.

Dr. G. Allan Roeher (Canada):

When a child is born and somebody says it is retarded, you panic. If that child was born with a heart defect, the situation is quite different. This is what we are dealing with. This happens to people because of the way society does this thing, and if we don't lick this problem, we can work ourselves down to the ground. Sure we will make some progress, we will help some kids, but we are not really getting to the core of the whole issue.

When a public relations man has a medical problem or a psychological problem, he goes to a professional person for advice and help. Unfortunately, when a professional person has a public relations problem, he does not go to the public relations person, he becomes his own public relations person. I should like to give you an example of how an event or two can do so much. One is what Mrs. Kennedy has done in her public messages.

Certainly Mrs. Kennedy and what she represents has done a lot to comfort a lot of parents.

We have had another similar experience in Canada. We spend some $15,000,000 in our combined government and voluntary organizations to set up some 14 university affiliated demonstration and research projects. We also have about 325 locals that are running some 500 programmes, just like all of you are doing. These people are actively doing public education.

Last year we had an Olympics for the retarded in Toronto. We had the big stadium and a big public relations firm and we got publicity all over the country. It was put on like the standard Olympics programme with all the flags, buntings etc. Some 1,500 persons were there. It was non-competitive.

The basic resistance to this programme came from the professional people; the teachers, the physical educators, the recreation people, the psychologists, who said, "Isn't that nonsense. These kids are going to be threatened. You are going to keep them up late and they are going to have a long trip, and what does it do to them?" "And this will interfere with our programme. You are expecting us to prepare them for an event and this is off routine." These were the people that we went without, eventually.

Well, the Press took hold of this, and we got millions of dollars worth of stories and materials. But an interesting thing

happened. The biggest public that you have are people interested in sports. When these things came on the media everybody said, "We did not know the retarded could do this kind of thing. Isn't that amazing, they run and they jump and things like that." A year and a half later if you take an opinion poll of the Canadian public and say "What do you know about mental retardation?" they won't mention our 14,000,000 dollar series, or our programmes for the parents, or what the professional people are doing, they say, "Wasn't that Olympics a wonderful thing! I did not know the retarded could do all these kind of things."

Your voluntary organizations have to take it one step further, and if they are not big enough for the job as a local body, then encourage them to mobilize on a national basis, or international basis if you like, so they can do certain things that have impact. Encourage this to go along side by side with all the other things that you people are doing. Then the Health Nurse becomes interested.

A good friend of mine who is the head of Paediatrics in a university tells his students, "If you want to be leaders in the community around the problem dealing with the disadvantaged, you go and join the voluntary organization. Listen to what they say, adopt what they say, and because you are the professional they will nominate you the leader". And it is just as easy as that to become the leader. But professional people, except for the people who are directly committed in the field, don't lead; they follow public opinion. So if you want your doctors and your nurses and your regular education teachers and so on behind you, your first step is changing public opinion. It is simple. Professionals react to the kinds of things that the public want, whether they are doctors, lawyers, or whatever.

The point of this session is that as professional people we are guilty of not helping to stimulate those agents in the community, voluntary organizations, business men and so on, of doing a parallel programme to what we are doing.

Mrs. C. DeCaires:

About two or three years ago, because of increasing numbers, our association had to move the school from a rented premises. We bought a property for E.C.$96,000. Two of us signed the agreement to purchase and we had $10,000. I saw visions of spending a couple of months in jail. The Jaycees then gave us $20,000 and the Lions gave us $18,000. We found we had $10,000 we did not know about, and so we were able to pay down the $48,000 necessary. We have since been able to pay off that $48,000 by active fund raising.

We have just acquired two acres of land adjoining the present site of the school for the workshop, and it is going to be built at a cost of $36,000. I knew where the Lions had $36,000 and I just got it from them. We have been very fortunate to get very active and substantial support from our Service Clubs.

Dr. G.A. Roeher:

The moral of this story is that it was a business man that went after it. You know, you are dealing with your own kind. Even as voluntary organizations, as parent groups, we don't know how to use business men. We want to involve them in inter-family problems. Don't do that. Involve them in the kinds of things that they know how to do and get a challenge out of accomplishing a major task. Here is a fine example.

Mother Joan Teresa:

We had a similar experience ourselves in Trinidad in getting the public interested. In the beginning we just could not get doctors interested in the home or in the work we were doing, they felt a lot of money was being wasted and so on. We knew that the Trinidad public loved plays and operettas, so we inaugurated an annual operetta and this has really put the home on the map.

The first performance the children put on we had about a half-full house. Now we have to increase it to three days, because people say, "Don't ever miss one of these shows. It is something you can't forget". Lately we have had to move the shows to other parts of the country. People have now proposed that we put it on at Queen's Hall. If people get to know that the retarded can do something that normal people can do, everybody becomes very interested.

Mr. G.W. Lee (U.K.):

In our society, we seek to do a two-fold job of raising money and raising our image at one and the same time. We have a galaxy of stars at our disposal in London, and all the great names of the films are ours to command. Nothing succeeds like success, and nothing is more dismal than failure; it is the initial exercise of getting the thing off the ground that is the difficulty.

The fact that the Press come to see the star at a rather bizarre situation does not really matter. The fact that they are there, means that you can then get them to write up your story. It is up to you from that point to make the story known.

In the end you are not really going to succeed in any sort of agency or organization, unless you are publicity conscious. And it is no use just having a good story to tell – good stories are not news.

No one has so far mentioned, I think, one of the most grievous aspects of the problem of being a parent of a mentally handicapped child. In no country in the world, can the news that you have given birth to a mentally handicapped child be seen as joyful news. There is a grievous lack of sensibility about the method of revelation. So much unnecessary harm, and suffering has attended the revelation of this particular piece of news.

It can be done in a better way then is usually utilized. Our concern is that there should be a code as to when and how it it should be done.

Mr. F. Hardy:

The American Medical Association has published a little booklet called "Mental Retardation for the Family Physician" for medical students. The reason this particular booklet is so successful is because it is geared to be used by medical students, and if medical students are using it, then the General Practitioners find that they had better read it too, because they don't want the young medical practitioner telling them how to do things.

Mrs. S. Francis:

On this question there was one point which I think we should emphasize. Material from other countries may be very useful but we need to have this adapted in our local dialect. There is a lot that can be done in development of literature, which is easily understood by local people with very little education.

Dr. H. Feldman:

In my experience in Jamaica among the underprivileged I see many children whose mental retardation is disguised by severe behaviour problems. Their mental retardation as far as the parents are concerned is disguised by the emphasis of the behaviour problem. I find that when you point out to these parents that the child is suffering from a handicap and it is not the question of treating from a punitive aspect, the mother is very often very much more tolerant, and very readily helped, particularly if the formal communication is done tactfully and

sympathetically. But the attitude of the lower socio-economic group to mental retardation, and the attitude of the middle classes is very different in this country, and the method of approach should therefore possibly be modified according to the particular social class.

Mother Joan Teresa:

I have had the painful experience where the medical practitioner informs the mother that the child is not retarded, and she continues to hope that this child will eventually develop and become normal. This might go on for years. Each time the child returns and the doctor administers treatment and nothing happens. Eventually the mother in desperation comes to the school for the retarded to ask for advice.

RECOMMENDATIONS

1. Every means should be adopted to bring the public in direct contact with the mentally retarded in as normal a way as possible to dispel misconceptions. This might be done in training and work situations and in other activities such as Olympics, and cultural activities for the mentally retarded.

2. All sources should be tapped, films, pamphlets, getting people to talk. But foreign information should be adapted to our culture. Local educational material could be made.

3. Women's groups, citizen's associations, and church groups, trade unions and other voluntary or social organizations should be used as vehicles for education.

4. Specific information about mental retardation should be provided in the curricula for nurses, social workers, teachers and ministers of religion, etc.

5. Modern techniques of communication and public relations should be used to create a favourable public opinion and win support. Professional public relations personnel should be utilised where possible. The participation of well known public figures attracts attention in news media.

FINAL SESSION

"The Future"

Chairman: Dr. Matthew A. C. Beaubrun (Jamaica)

September 9, 1970.

During this session the recommendations from each preceeding session were enumerated.

Proposals were made and accepted for the holding of a Second Caribbean Mental Retardation Conference in Puerto Rico in 1972. A further proposal for a Regional Association on Mental Retardation was made and a Steering Committee was nominated to implement immediately the following points:

(1) To appoint a Co-ordinating Committee

(2) To produce a press release for the conference

(3) To organise the recommendations under the headings of those concerning Governments, Universities, Local Associations and the formation of a Secretariat.

The Steering Committee consisted of the following:

Dr. M.A.C. Beaubrun, Chairman (Jamaica)
Dr. M.J. Thorburn, Secretary (Jamaica)
Dr. A.C. Graham (Barbados)
Dr. Frank Williams (Guyana)
Mrs. Nesta Patrick (Trinidad)
Dra. Dora Sarasola (Dominican Republic)
Professor Delia Lugo (Puerto Rico)

During the next two days the Steering Committee with the assistance of Mr. G.W. Lee produced the following set of recommendations:

ESTABLISHMENT OF A CO-ORDINATING CENTRE OR SECRETARIAT

The meeting recommends strongly the establishment of a "Caribbean Co-ordinating Centre" as a forerunner of a "Caribbean Institute of Mental Retardation".

This would be established where communications with expert personnel are easy and expert advice is readily available.

The functions would include:

1. Provision of information about needs in the area served

2. Collating information on resources and methods used in different areas.

3. Providing personnel to go around less developed areas to conduct seminars, short training programmes to educate para-medical personnel to deal with mentally retarded problems, and provide advice and counselling.

4. Provision of a library or centre for the dissemination of information and responsibility for the circulation of a bulletin.

5. To establish contact and become members of the International organisations for mental retardation.

Great emphasis is placed on the fact that any training provided should be conducted in the local situation and any outside expert advice should be obtained from people who are aware of the local area problems and situation.

It must be recognised that the above functions would require the establishment of a permanent secretariat.

A Co-ordinating Committee for a Caribbean Association on Mental Retardation has been formed with the following members:

Dr. M.A.C. Beaubrun, Chairman (Jamaica)
Dr. M.J. Thorburn, Secretary (Jamaica)
Mr. Paul Levy (Jamaica)
Mr. Cecil Jacobs (St. Vincent)
Mrs. Nesta Patrick (Trinidad)
Dr. Jordi Brossa (Dominican Republic)
Dr. Henry Podlewski (Bahamas)
Mr. Cecil DeCaires (Barbados)
Mrs. Joan Coronel Peterson (Aruba)
Sra. E. Purcell de Hernandez (Puerto Rico)
Dr. L. Bijou (Haiti)

Consultants

Dr. James F. Garrett (U.S.A.)
Dr. G. Allan Roeher (Canada)
Mr. George W. Lee (U.K.)
Mr. Francis Hardy (U.S.A.)
Miss Frances McGrath (U.S.A.)

RECOMMENDATIONS TO GOVERNMENTS OF THE CARIBBEAN AREA

Although accurate facts on the size of the problem of mental retardation in individual areas are not available, the conference concluded that there was a desperate need for facilities and personnel in most areas. Approximately 3% of any population are likely to be retarded. We therefore recommend to Caribbean Governments the following:

1. The problem of mental retardation is a national responsibility.

2. We feel that the prevailing pre-school environment contributes to milder degrees of mental retardation, which cannot be adequately dealt with by the existing educational system. To avoid the unnecessary wastage of human resources and consequent drain on the economy, preventive steps in this problem would involve:

   (a) Providing pre-school education, day care centres nursery education and parent instruction in providing a stimulating environment.

   (b) We feel that one important step would be the introduction of conceptual teaching methods. Where creches and day nurseries exist, we strongly urge the introduction of simple modern methods of child play and stimulation of child development.

3. There should be provision in the educational system for psychological advice and guidance for children with learning problems in order to ascertain as early as possible cases who need special help.

4. There should be provision in the school system of special resource classes for the mildly retarded.

5. Information about diagnosis and handling of mental retardation should be included in the training of nurses, social workers, teachers, medical students, and nursery school teachers.

6. It is strongly felt that at least one teacher training college which has a special school for the retarded in the vicinity should offer an additional optional course in special edution. Use could be made of the local school for demonstration and training.

7. The recognition of the need for inclusion in the University curricula of courses in special education and psychology is strongly urged.

RECOMMENDATIONS TO THE UNIVERSITIES OF THE CARIBBEAN AREA

We would like to draw the attention of University Authorities to the following recommendations:

1. The introduction of the following into University Curricula:

   (i) Courses in psychology and child development.

   (ii) Courses in mental retardation teacher training such as those offered in other Universities.

2. Studies on the following:

   (i) The effect of West Indian culture on the environment and mental retardation.

   (ii) The development of psychological and developmental tests suitable to the Caribbean culture.

   (iii) The causes and effects of behaviour disorders and their relationship to mental retardation.

   (iv) Genetic counselling should be made available in a clinical setting in paediatric departments.

RECOMMENDATIONS TO NATIONAL AND LOCAL ASSOCIATIONS FOR THE MENTALLY HANDICAPPED

1. Every territory should have a group or association concerned with mental retardation as opposed to mental illness.

2. There should be a Co-ordinating Body for the Caribbean.

3. Parents should be involved in all types of educational programmes, especially where the child is not placed in a home or school.

4. Efforts have to be made to provide training. In the interim while Governments are being persuaded to take on training, efforts should be made to train unqualified persons, with the assistance of expert personnel, e.g. by means of Summer Schools.

5. Efforts should be made to establish a multidisciplinary approach to diagnosis, assessment and placement. Associations should endeavour to combine the efforts of psychologist, social worker, child guidance clinics and paediatricians with placement and counselling, so that there is direct liaison between voluntary and professional facilities.

6. In sheltered workshop facilities, efforts should be made to provide self sustaining occupation and work rather than trying to train to compete with able bodied workers in unindustrialised areas.

7. Efforts should be made to train educable retarded so that they are socially adjusted and can perform in open employment. The attention of Government and other employers of labour should be drawn to the work potential offered by the retarded in jobs not always attractive to the able bodied.

8. Public Relations

   a) This is a major responsibility of a national association. Educational programmes of the nature of mental retardation in order to dispel misconceptions and fears should be aimed at all levels of the society especially employers, trade unions, teachers, parents, and the general public.

   b) Every means should be sought to bring the public in contact with the retarded in their activities by sporting events, plays, concerts and other cultural activities.

   c) All sources of information should be tapped; films, leaflets, talks, but should be adapted to the local environment.

   d) Modern techniques of communication and public relations should be used and expert advice in this field should be utilised where possible. Participation of popular figures should be sought.

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